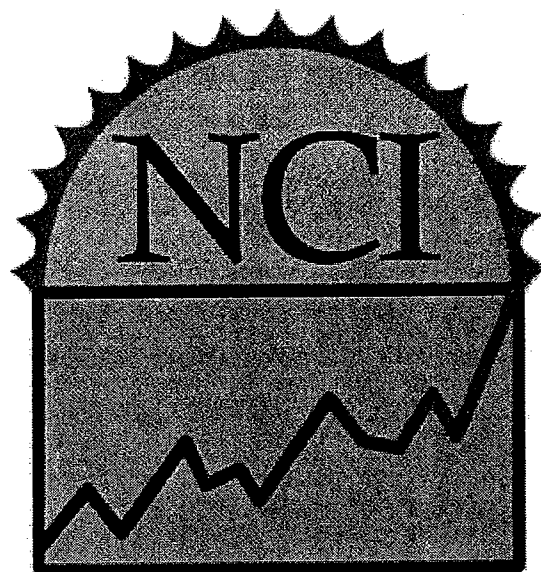


Child Family Survey

Final Report – January 2004
2002-2003 Data



NATIONAL CORE INDICATORS

A Collaboration of
National Association of State Directors of Developmental Disabilities Services and
Human Services Research Institute

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Organization of Report

Six states and one local developmental disability authority conducted the National Core Indicators (NCI) Child Family Survey during the 2002-2003 project year and submitted data. The Child Family Survey was administered to families having a child with disabilities living in the family's home. This Preliminary Report provides a summary of results, based on the data submitted by June 2003.

This report is organized as follows:

I. INTRODUCTION

This section provides an overview of the National Core Indicators, and a brief history of the development, administration, and participation of states in the NCI Child Family Survey.

II. CHILD FAMILY SURVEY

This section briefly describes the structure of the survey instrument.

III. METHODS

This section illustrates the protocol used by states to sample participating families, administer the survey, and convey the resulting data for analysis. It also includes information on the statistical methods used by Human Services Research Institute staff to aggregate and analyze the data.

IV. RESULTS

This section provides aggregate and state-by-state results for demographic, service utilization, service access and delivery, satisfaction and outcome data.

V. DISCUSSION OF RESULTS

This section provides aggregate and state-by-state results for demographic, service utilization, service planning, access and delivery, choice and control, community connections, satisfaction and outcome data. It also provides an overall view of the aggregate survey results.

I. Introduction

Overview of National Core Indicators

In 1996, the NASDDDS Board of Directors launched the Core Indicators Project (CIP). The project's aim is to support state developmental disabilities authorities (SDDAs) in developing and implementing performance/outcome indicators and related data collection strategies that will enable them to measure service delivery system performance. The project strives to provide SDDAs with sound tools in support of their efforts to improve system performance and thereby to better serve people with developmental disabilities and their families. NASDDDS' active sponsorship of CIP facilitates states pooling their knowledge, expertise and resources in this endeavor.

Phase I – Phase I of CIP began in 1997 when the CIP Steering Committee selected a “candidate” set of 61 performance/outcome indicators (focusing on the adult service system), in order to test their utility/feasibility. Seven states agreed to conduct a field test of these indicators, including administering the project's consumer and family surveys and compiling other data. Field test data were transmitted to project staff during the summer of 1998. The results were compiled, analyzed and reported to participating states in September 1998.

1999 - 2000 – Phase II of CIP was launched in 1999, with a deadline for collection of 1999 data set in June 2000. During Phase II, the original indicators were revised and data collection tools and methods were improved. The new (Version 2.0) indicator set consisted of 60 performance and outcome indicators. Twelve states (Arizona, Connecticut, Kentucky, Massachusetts, Minnesota, Nebraska, North Carolina, Pennsylvania, Rhode Island, Virginia, Vermont, Washington) participated in Phase II, and this data is considered baseline project data. .

2000 - 2001 (Phase III) – In the spring and summer of 2001, data from the year 2000 was collected. At this time, it was decided to switch from describing the data sets as “phases” of the project to describing them by year in which the data was collected. Therefore, Phase III was now 2000 Data. Moving forward, four additional states joined the project (Delaware, Iowa, Montana, Utah) and the project expanded its scope to include services for children with developmental disabilities and their families. Also during this time, the CIP staff and participants continued to develop and refine the indicators, and recruit additional states to participate in the project. Technical reports for Phase II (1999 Data) and 2000 Data, along with other selected documents are available online at www.hsri.org/cip/core.html

2001 - 2002 (Phase IV) – The Core Indicators Project (CIP) officially changed its name to the National Core Indicators (NCI) to reflect its growing participation and ongoing status. Participation in the National Core Indicators is entirely voluntary. For this year's round of data collection, seven new states and one local DD authority joined NCI (Alabama, Orange County in California, Hawaii, Illinois, Indiana, Oklahoma, West Virginia, Wyoming). During 2001-2002, 20 states and one local authority were active in NCI.

2002 – 2003 (Phase V) - Project participation continues to grow. During this past year, Maine, South Carolina and South Dakota have joined the National Core Indicators effort.

The figure on the following page summarizes state participation in the National Core Indicators since its inception through the 2002-2003 data collection cycles. States are listed if they participate in one or more of the NCI activities (e.g., consumer survey, family surveys, expenditure/utilization data, etc.).

Table 1 State Participation in National Core Indicators				
Phase I Field Test	Phase II 1999-2000	Phase III 2000-2001	Phase IV 2001-2002	Phase V 2002-2003
AZ CT MO NE PA VT VA	AZ	AZ		AL
	CT	CT	AZ	AZ
				CA - Orange Co.
			CT	CT
		KY	DE	DE
	NE	MA		HI
		MN		IN
	PA			IA
	VT	NE	IA	KY
	VA	NC	KY	MA
		PA	MA	
		RI	NE	NE
			NC	NC
		VT		OK
		WA	PA	PA
			RI	RI
			UT	
			VT	
			WA	VT
				WA
				WV
				WY
Denotes first year of participation in NCI				

Family Indicators

Obtaining direct feedback from families is an important means for states to gauge satisfaction with services and supports as well as to pinpoint potential areas for quality improvement. The results garnered from family surveys enable a state to establish a baseline against which to gauge changes in performance over time. In addition, these results permit a state to compare its own performance against other states.

Previously, there were two family-related indicators under the **Consumer Outcomes** domain of the Phase II Core Indicators. The two sub-domains were **Supporting Families** and **Family Involvement**. From these sub-domains, three family surveys had been designed: the Adult Family Survey; the Children Family Survey; and the Family/Guardian Survey.

During this past year, new Family Indicators were developed and approved by the NCI Steering Committee. The table below details the new Sub-Domains, Concerns, and Indicators, and identifies the survey instruments in which the indicators are explored. The new Sub-Domains include: **Information and Planning, Choice and Control, Access and Support Delivery, Community Connections, Family Involvement, Satisfaction and Outcomes..** Each of the three family surveys follow, in structure, this new framework.

Table 2
Family Indicators

DOMAIN	FAMILY INDICATORS The project's family indicators concern how well the public system assists children and adults with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.		
SUB-DOMAIN	CONCERN	INDICATOR	DATA SOURCE
Information & Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.	The proportion of families who report they are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	All Surveys
		The proportion of families who report they have the information needed to skillfully plan for their services and supports.	All Surveys
		The proportion of families reporting that their support plan includes or reflects things that are important to them.	All Surveys
		The proportion of families who report that staff who assist with planning are knowledgeable and respectful.	All Surveys
Choice & Control	Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.	The proportion of families reporting that they control their own budgets/supports (i.e. they choose what supports/goods to purchase).	Children & Adult Family Surveys
		The proportion of families who report they choose, hire and manage their service/support providers.	All Surveys
		The proportion of families who report that staff are respectful of their choices and decisions.	All Surveys
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.	The proportion of eligible families who report having access to an adequate array of services and supports.	All Surveys
		The proportion of families who report that services/supports are available when needed, even in a crisis.	All Surveys
		The proportion of families reporting that staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication .	All Surveys
		The proportion of families who report that service and support staff/providers are available and capable of meeting family needs.	All Surveys
		The proportion of families who report that services/supports are flexible to meet their changing needs.	All Surveys
		The proportion of families who indicate that services/supports provided outside of the home (e.g., day/employment, residential services) are done so in a safe and healthy environment.	Both Adult Surveys
Community Connections	Families/family members use integrated community services and participate in everyday community activities.	The proportion of families/family members who participate in integrated activities in their communities.	All Surveys
		The proportion of families who report they are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	All Surveys
Family Involvement	Families maintain connections with family members not living at home.	The proportion of families/guardians of individuals not living at home who report the extent to which the system supports continuing family involvement.	Family/Guardian Survey
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.	The proportion of families who report satisfaction with the information and supports received, and with the planning, decision-making, and grievance processes.	All Surveys
Family Outcomes	Individual and family supports make a positive difference in the lives of families.	The proportion of families who feel that services and supports have helped them to better care for their family member living at home.	Children & Adult Family Surveys

II. Child Family Survey

Background

This report focuses on the Child Family Survey.

2000 - 2001 – In the year 2000, five states participated and mailed out over 5,000 Child Family Surveys. Response rates among states ranged from 30% to 57%, with approximately 2,000 completed surveys returned.

2001 - 2002 – In the year 2001, four states and one local developmental disability authority participated and mailed out over 6,500 Child Family Surveys. Response rates among states ranged from 26% to 49%, with approximately 1,800 completed surveys returned.

2002 - 2003 – The results from this survey are explored, in detail, in this report.

State Participation

Below is a figure indicating state participation in the Child Family Survey since its inception.

Table 3 State Participation in NCI Children Family Survey (Children Living at Home)				
Phase I Field Test	Phase II 1999 Data	Phase III 2000 Data	Phase IV 2001 Data	Phase V 2002 Data
NA	NA	AZ MN NC UT WA	CA - Orange Co. NE NC UT VT	AZ CA - Orange Co. MA SC SD WA WY

Survey Instrument

States that administer the Child Family Survey agree to employ the NCI's base instrument and questions. If it wishes, a state may include additional questions to address topics not dealt with in the base instrument. Since all states use the standard questionnaire, the results are comparable state-to-state. Here, we describe the Child Family Survey developed. Further on in the report, we discuss how the surveys were administered and how the results were analyzed.

The Child Family Survey used in 2002-2003 not only asks families to express their overall level of satisfaction with services and supports, it also probes specific aspects of the service system's

capabilities and effectiveness. Along with demographic information, the survey includes questions related to: the exchange of information between individuals/families and the service system; the planning for services and supports; access and delivery of services and supports; connections with the community; and outcomes. Combined, this information provides an overall picture of family satisfaction within and across states.

Demographics – The survey instrument begins with a series of questions tied to characteristics of the child with disabilities (e.g., child's age, race, type of disability). It is then followed by a series of demographic questions pertaining to the respondent (e.g., respondent's age, health status, relationship to individual).

Services Received – A brief section of the survey asks respondents to identify the services and supports their family/child receives.

Service Planning, Delivery & Outcomes – The survey then contains several categories of questions that probe to specific areas of quality service provision (e.g., information and planning, access and delivery of services, community connections). Each question is constructed so that the respondent can select from three possible responses ("always or usually", "sometimes", and "seldom or never"). Respondents also have the option to indicate that they don't know the answer to a question, or that the question is not applicable for their family/family member.

Additional Comments – Finally, the survey provides an opportunity for respondents to make additional open-ended comments concerning their family's participation in the service system.

III. Methods

Sampling & Administration

States administered the Child Family Survey by selecting a random sample of 1,000 families who: a) have a child with developmental disabilities living at home, and b) receive service coordination and at least one additional service or support. Children were defined as individuals with disabilities under age 22. A sample size of 1,000 was selected in anticipation that states would obtain at least a 40% return rate, yielding 400 or more usable responses per state. With 400 usable responses per state, the results may be compared across states within a confidence level of $\pm 10\%$. In states where there were fewer than 1,000 potential respondent families, surveys were sent to all eligible families.

Each state entered survey responses into a standard file format and sent the data file to HSRI for analysis. As necessary, HSRI personnel "cleaned" (i.e., excluded invalid responses) based on three criteria:

- ♦ The question "Does your child live at home with you?" was used to screen out respondents who received a survey by mistake. For instance, if a respondent indicated that their child with disabilities lived outside of the family home, yet received the Child Family Survey, their responses were dropped.
- ♦ If the respondent indicated that their family member was over the age of 21, their responses were dropped.
- ♦ If demographic information was entered into the file, but no survey questions were answered, these responses were also dropped.

Response Rates

During the 2002-2003 data year, six states and one local developmental disability authority administered the Child Family Survey. Table 4 shows the number of surveys each state mailed out, the number and percent returned, and the number of valid surveys accepted for inclusion in data analysis.

Table 4			
Child Family Survey - State Response Rates			
State	Surveys Mailed	Surveys Returned (%)	Usable Surveys
Arizona	1,200	358 (30%)	347
CA-Orange Co.	4,501	923 (21%)	923
Massachusetts	1,500	378 (25%)	370
South Carolina	*	118 (*)	104
South Dakota	342	174 (51%)	171
Washington	1,500	490 (33%)	476
Wyoming	420	187 (45%)	187
Overall		1,299	742
*denotes data missing			

The desired response rate (the percentage of surveys returned versus the number mailed) to these surveys is 40%. Table 4 indicates the response rates by state, based on the number of returned surveys entered into the database and submitted for analysis, compared to the total number mailed out.

Data Analysis

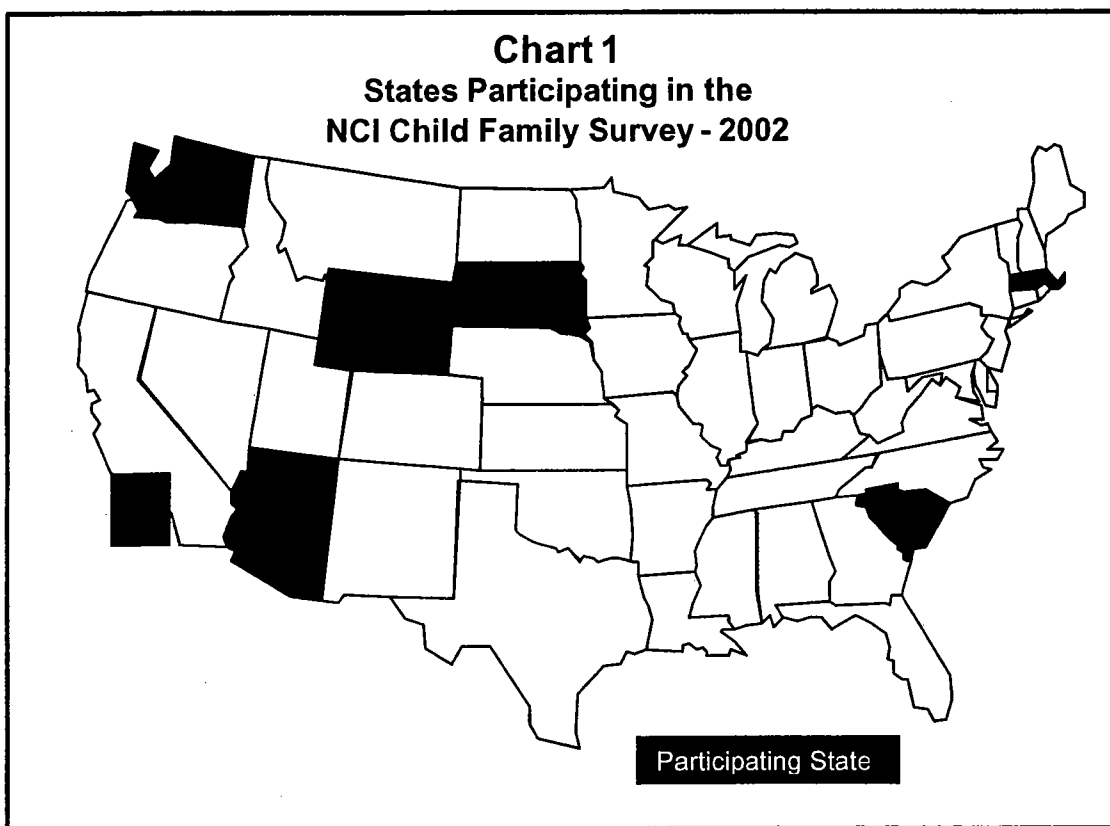
NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Data is entered by each state, and files are submitted to HSRI for analysis. All data is reviewed for completeness and compliance with standard NCI formats. The data files are cleaned and merged, and invalid responses are eliminated. HSRI utilizes SPSS (v. 10) software for statistical analysis and N6 software for support in analysis of open-ended comments.

IV. Results

The figures below provide the findings from the Child Family Survey. Findings are presented in aggregate, as well as by state.

Participating States

- ♦ Six states (Arizona, Massachusetts, South Carolina, South Dakota, Washington and Wyoming) and one local developmental disabilities authority (Orange County Regional Center in California) provided data for this Report.



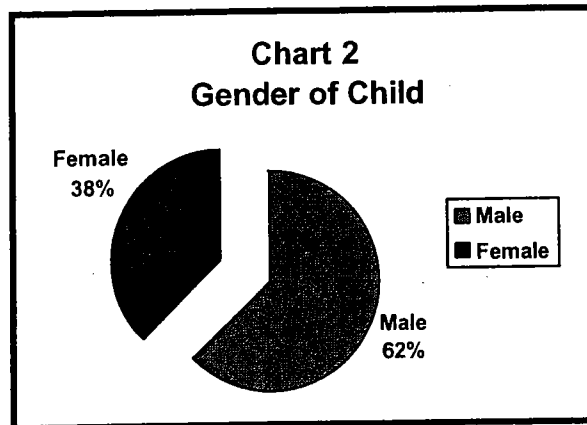
Characteristics of Children with Disabilities

This section provides information about the child with disabilities living in the household.

Gender of Family Member

- ♦ On average, across the states, 62% of children with disabilities were male, 38% were female.

Table 5 Gender		
State	% Male	% Female
AZ	64	36
CA-RCOC	68.9	31.1
MA	66.0	34.0
SC	59.6	40.4
SD	51.5	48.5
WA	61.6	38.4
WY	65.6	34.4
Total n	624	188
Total %	64.0	36.0
State Avg	62.5	37.5



Age of Family Member

- ♦ Across all participating states, the average age of children with disabilities was 9.4, with a range in age from 0 to 21.

Table 6 Age of Child		
State	Average Age	Range
AZ	7.7	1-21
CA-RCOC	9.2	0-19
MA	10.0	0-19
SC	7.1	1-17
SD	9.1	1-18
WA	10.5	1-18
WY	12.3	2-21
Total n	491	
Total Avg	9.5	0-21
State Avg	9.4	

Race of Family Member

In this category, respondents could indicate one or more races/ethnicities. For this reason, the percentages may not total 100%.

- ♦ Across all states, 72% of the children with disabilities were White, 9% were Black/African-American, 4% were American Indian/Alaska Native, 4% were Asian-American, 1% were Native Hawaiian/Pacific Islander, 5% were Mixed Races, and 12% were Hispanic/Latino.

Table 7 Race/Ethnicity of Child (%)								
State	White	Black/ African American	Asian	American Indian/ Alaska Native	Native Hawaiian/ Pacific Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
AZ	55.5	6.4	3.5	9.5	0.3	7.8	0.3	24.6
CA-RCOC	43.7	1.9	14.7	2.0	0.9	6.1	1.0	36.8
MA	87.3	4.7	1.1	3.3	0.0	4.4	0.3	5.2
SC	57.9	40.8	2.1	1.0	3.1	4.1	4.1	5.2
SD	88.3	2.9	1.2	4.1	0.0	3.5	0.6	0.6
WA	77.4	5.2	6.0	4.7	1.5	5.8	1.3	7.3
WY	93.0	1.6	0.5	2.7	0.5	2.1	0.0	5.3
Total n	1,689	126	180	98	20	159	21	455
Total %	65.0	4.5	7.1	3.9	0.8	5.5	0.9	16.3
State Avg %	71.3	9.1	4.2	3.9	0.9	4.0	1.0	12.1

More Than One Person with Disabilities Living in Household

- ♦ On average, 17% of households include more than one individual with a developmental disability. However, the range varied dramatically from 11% in South Dakota to 27% in Massachusetts.

Table 8 More Than One Person in Household with a Developmental Disability		
State	% Yes	% No
AZ	17.8	82.2
CA-RCOC	15.0	85.0
MA	27.0	73.0
SC	12.6	87.4
SD	10.7	89.3
WA	23.9	76.1
WY	11.8	88.2
Total n	1,450	2,077
Total %	18.1	81.9
State Avg. %	17.0	83.0

Level of Mental Retardation of Family Member

- ♦ On average, 78% of children with disabilities required moderate to complete levels of assistance with activities of daily living. Fewer than one-quarter (22%0 of children required little or no assistance with these activities.

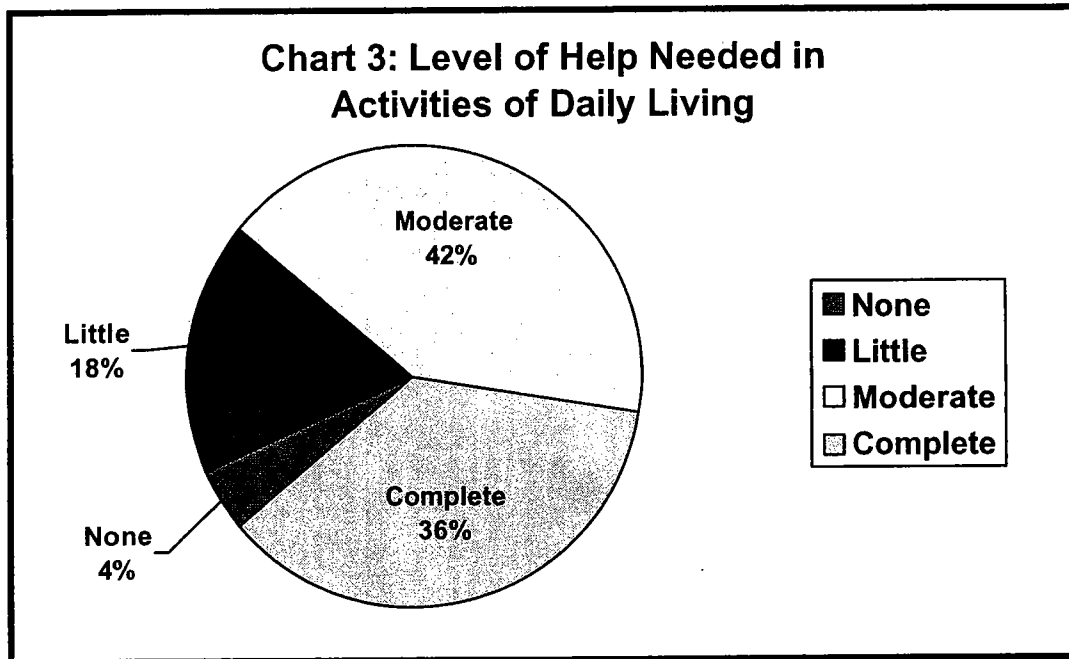


Table 9 Level of Help with Daily Activities				
State	None	Little	Moderate	Complete
AZ	3.6	13.4	44.8	38.3
CA-RCOC	5.9	19.9	32.9	41.4
MA	6.0	21.1	43.1	29.8
SC	8.1	21.2	43.4	27.3
SD	1.8	14.2	42.0	42.0
WA	1.7	14.9	48.2	35.2
WY	3.8	19.4	36.0	40.9
Total n	112	440	1,005	221
Total %	4.5	17.9	40.1	37.6
State Avg %	4.4	17.7	40.9	37.0

Family Member's Disabilities

- ♦ Many families indicated that their children have mental retardation (43%) and/or other developmental disabilities (32%). Additionally, many children experience other disabilities, such as autism (26%), physical disabilities (26%), seizure disorders (25%), communication disorders (24%), vision or hearing impairments (22%), and/or cerebral palsy (21%).

Table 10A Disabilities of Child						
State	Mental Retardation	Other Dev. Disability	Mental Illness	Autism	Cerebral Palsy	Brain Injury
AZ	36.8	33.0	3.8	20.3	26.1	7.0
CA-RCOC	37.3	13.4	1.8	37.3	16.0	5.2
MA	40.2	32.2	6.3	37.1	16.9	5.4
SC	36.3	40.7	3.3	21.1	14.4	3.3
SD	45.3	34.1	2.4	15.9	27.6	11.2
WA	36.8	37.0	4.9	27.6	21.0	7.5
WY	66.8	29.9	3.2	21.4	22.5	12.8
Total n	1013	675	88	752	26	71
Total %	40.3	26.3	3.5	29.9	19.5	6.3
State Avg. %	42.8	31.5	3.7	28.8	20.5	16.2

Table 10B Disabilities of Child							
State	Seizure Disorder/ Neurological Problem	Chemical Dependency	Vision or Hearing Impairments	Physical Disability	Communication Disorder	Down Syndrome	Other Disability
AZ	24.4	0.3	29.0	23.2	20.0	14.2	24.1
CA-RCOC	16.9	0.5	13.3	14.9	22.0	16.7	11.7
MA	21.3	0.5	22.1	22.9	24.8	12.5	25.6
SC	23.3	1.1	16.7	26.7	19.8	10.1	28.9
SD	30	0.0	22.4	37.6	25.3	*	17.6
WA	31.7	0.4	25.7	26.3	25.9	12.0	27.4
WY	28.9	0.5	23.5	26.7	27.3	16.6	26.7
Total n	586	11	516	557	588	880	515
Total %	23.3	0.4	20.6	22.2	23.4	14.3	20.5
State Avg. %	25.2	0.5	21.6	25.5	23.6	13.7	23.1

* Question not asked in South Dakota

Characteristics of Respondents

This section provides information about survey respondents. Respondents are the individuals who completed the survey forms, not the individual with disabilities living in the household.

Age of Respondent

- ♦ Across all states, nearly three-quarters (71%) of respondents fell into the age category of 35 to 54 years old. Twenty-one percent of respondents were under 35, and the remaining 7% were over 55.

Table 11 Age of Respondent (%)				
State	Under 35	35-54	55-74	75 or Older
AZ	39.5	55.0	5.2	0.3
CA-RCOC	18.0	71.9	9.2	0.9
MA	11.9	82.1	5.4	0.5
SC	24.3	63.1	10.7	0.1
SD	17.2	81.1	1.8	0.0
WA	21.3	71.5	7.0	0.2
WY	18.2	72.7	8.2	0.0
Total n	534	525	183	11
Total %	20.9	70.3	7.3	1.5
State Avg %	21.4	70.1	6.9	1.6

Relationship of Respondent to Individual with Disabilities

- ♦ The vast majority of respondents were parents of children with disabilities (95%). The remaining respondents were grandparents (4%), or others (1%).

Table 12 Relationship to Child with Disabilities (%)				
State	Parent	Sibling	Grand-parent	Other
AZ	96.0	0.3	3.5	0.3
CA-RCOC	97.8	0.0	1.6	0.5
MA	97.0	0.5	1.6	0.8
SC	91.2	0.0	5.9	2.9
SD	97.6	0.0	1.8	0.6
WA	94.9	0.0	4.4	0.6
WY	93.0	0.0	5.9	1.1
Total n	2,463	13	74	11
Total %	96.3	0.1	2.9	0.7
State Avg %	95.4	0.1	3.5	1.0

Respondent's Role as Primary Caregiver

- ♦ In total, 98% of all respondents were the primary caregiver for their child with disabilities. This was consistent across all of the states.

Table 13
Respondent is Primary Caregiver

State	% Yes	% No
AZ	99.1	0.9
CA-RCOC	97.6	2.4
MA	98.3	1.7
SC	99.0	1.0
SD	98.8	1.2
WA	96.6	3.4
WY	97.8	2.2
Total n	2,486	34
Total %	97.8	2.2
State Avg %	98.1	1.9

Health of Respondent

- ♦ Most respondents (individuals who completed the surveys) indicated that they were in good (52%) or excellent (30%) health. Eighteen percent, however, categorized their health as being fair or poor.

Table 14
Health of Respondent (%)

State	Excellent	Good	Fair	Poor
AZ	34.8	47.5	13.9	3.8
CA-RCOC	30.6	48.3	19.1	2.0
MA	35.3	46.7	15.8	2.2
SC	25.2	52.4	18.4	3.9
SD	29.0	57.4	12.4	1.2
WA	24.7	54.3	18.7	2.3
WY	30.5	54.5	13.4	1.6
Total n	775	1,282	213	55
Total %	30.4	50.3	17.8	2.5
State Avg %	30.0	51.6	16.8	2.6

Household Income

- ◆ Nearly half (43%) of respondents had an annual household income (including all wage earners within the household) of \$25,000 or less. 28% had a household income between \$25,001 and \$50,00, and 29% had an income over \$50,000.

Table 15 Household Income					
State	Below \$15,000	\$15,001 - \$25,000	\$25,001 - \$50,000	\$50,001 - \$75,000	Over \$75,000
AZ	26.6	21.9	23.8	13.4	13.4
CA-RCOC	22.7	22.2	21.3	14.1	19.7
MA	17.8	9.9	26.6	17.8	28.0
SC	41.1	24.2	18.9	6.3	9.5
SD	15.5	23.6	41.0	12.4	7.5
WA	24.2	15.3	30.2	19.9	10.4
WY	20.0	16.0	35.4	23.4	5.1
Total n	549	453	639	382	30
Total %	22.8	18.8	26.5	15.2	6.2
State Avg. %	24.0	19.0	23.5	15.0	8.5

Services and Supports Received

- ♦ Across participating states, on average, specialized services and supports were most often utilized (74%) by families having a child with disabilities.
- ♦ Additionally, 43% used out-of-home respite, 40% received SSI financial support, 39% obtained in-home supports, and 38% received other types of financial support.

Table 16
Services and Supports Received (%)

State	SSI financial support	Other financial support	In-home support	*Out-of-home respite care	Early intervention	Transportation	Specialized services/ supports
AZ	41.1	13.4	45.4	29.9	25.1	15.4	84.2
CA-RCOC	34.8	11.0	26.1	36.3	20.0	11.8	59.3
MA	28.9	60.2	36.5	18.5	11.3	6.8	68.7
SC	52.9	20.2	26.0	22.8	40.4	16.0	62.8
SD	39.1	64.0	25.9	53.0	26.1	10.4	85.9
WA	40.5	54.7	54.9	68.3	5.5	11.8	73.0
WY	40.2	42.9	54.7	75.3	10.1	11.8	81.6
Total n	932	764	922	1043	407	281	
Total Avg %	37.3	32.7	37.6	42.3	17.3	12.9	70.3
State Avg %	39.6	38.1	38.5	45.4	19.8	12.9	73.3

Please Note: Washington data reflects respondents receiving either in-home or out-of-home respite care.

National Core Indicators

In these next several sections, the questions and results are discussed that tie directly to the National Core Indicator domains for assessing service and support quality. These questions are grouped as they pertain to 1) information and planning; 2) access and delivery of services and supports; 3) choice and control; 4) community connections; and 5) overall satisfaction and outcomes.

For each question, a Figure and Table is provided.

- ♦ The Figure illustrates the State Average results (i.e., the average percentage across the six states and one local DD authority that conducted this survey).
- ♦ The Table details individual state results, total percentage (i.e., the percentage of all respondents) and state average (i.e., the average percentage of the state-by-state results).
- ♦ In the Tables, a (↑) next to a state name indicates, that its results are **5% or more ABOVE** the state average among respondents who answered “Yes or Most of the Time” to each question.
- ♦ In the Tables, a (↑↑) next to a state name indicates, that its results are **10% or more ABOVE** the state average among respondents who answered “Yes or Most of the Time” to each question.
- ♦ A (↓) next to a state name indicates that its results are **5% or more BELOW** the state average among respondents who answered “Yes or Most of the Time” to each question.
- ♦ A (↓↓) next to a state name indicates that its results are **10% or more BELOW** the state average among respondents who answered “Yes or Most of the Time” to each question.
- ♦ In general, when a Table has many arrows (up and down), it indicates that there is considerable variance in results among states. When there are few arrows, responses across states are more uniform.

Following all of the individual question results, an overview of results by topic grouping (e.g., information and planning, choice and control) is offered, providing a crude overview of how states measured up, overall, against the state averages.

Information and Planning

- ♦ Across states, fewer than half (45%) of respondents indicated they regularly receive information about the services and supports available to them. Individual state results varied considerably, ranging from 30% in Washington and Massachusetts to 63% in Orange County, CA.

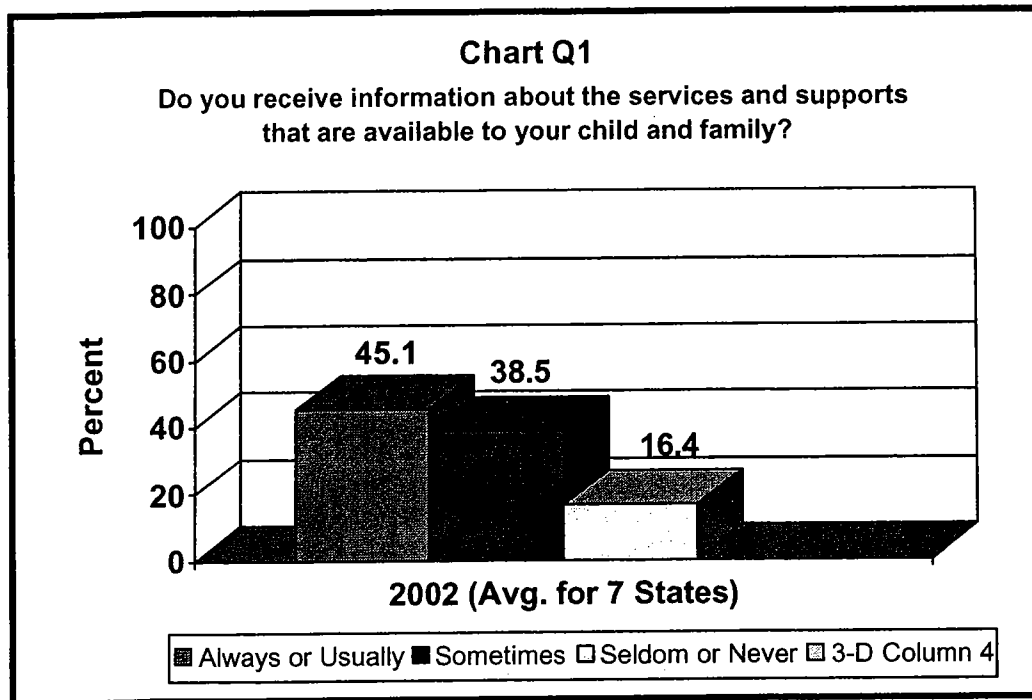


Table Q1

Do you receive information about the services and supports that are available to your child and family?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		44.8	37.9	17.3	330
CA-RCOC	↑↑↑	63.4	29.4	7.2	887
MA	↓↓↓	31.2	45.1	23.7	359
SC		49.0	32.7	18.4	98
SD	↑↑↑	55.6	36.7	7.7	169
WA	↓↓↓	29.9	41.5	28.6	465
WY		41.8	46.2	12.1	182
Total %		47.3	36.9	15.8	Total = 1765
State Average		45.1	38.5	16.4	Total = 71

- ♦ Among those who receive information, over half (60%) found the information easy to understand, while the remaining 40% found the information, at least sometimes, difficult to understand.

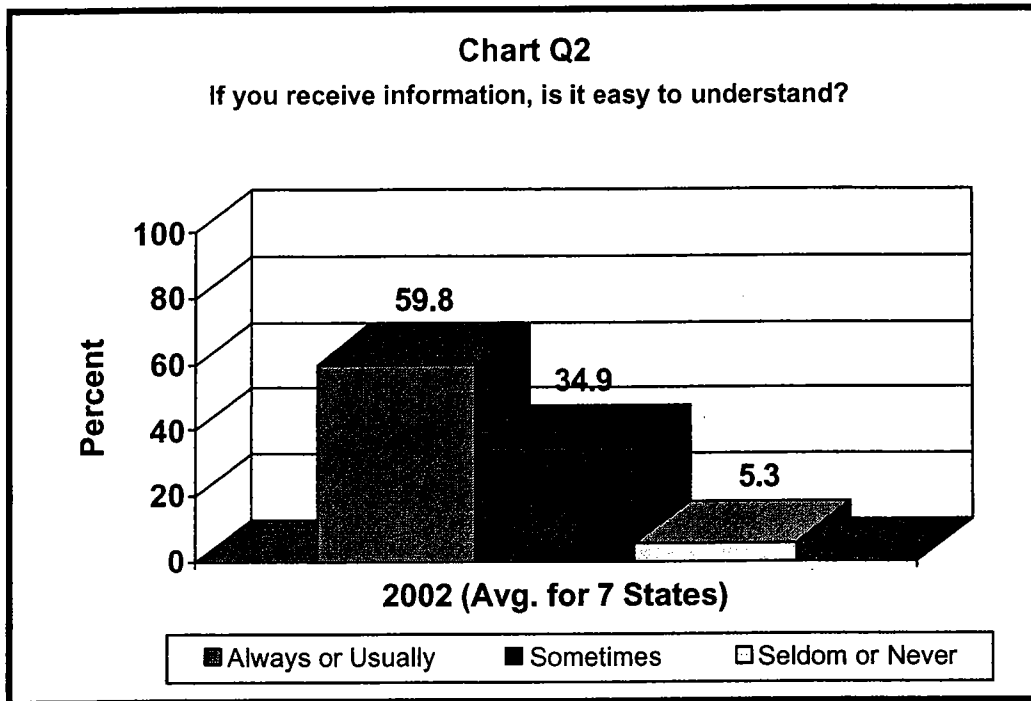


Table Q2
If you receive information, is it easy to understand?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		61.2	33.3	5.5	309
CA-RCOC	↑	66.2	29.3	4.6	851
MA		60.8	34.1	5.1	314
SC		60.0	34.4	5.6	90
SD	↑↑	72.0	25.6	2.4	168
WA	↓↓	48.5	42.3	9.2	402
WY	↓	50.0	45.3	4.7	172
Total		60.7	33.9	5.5	1,921
State Average		59.8	34.9	5.3	1,018

- ♦ Across states, half (49%) of respondents indicated they regularly receive information about their child's disability or development. Once again, individual state results varied quite a bit, ranging from 33% in Washington to 60% in Arizona.

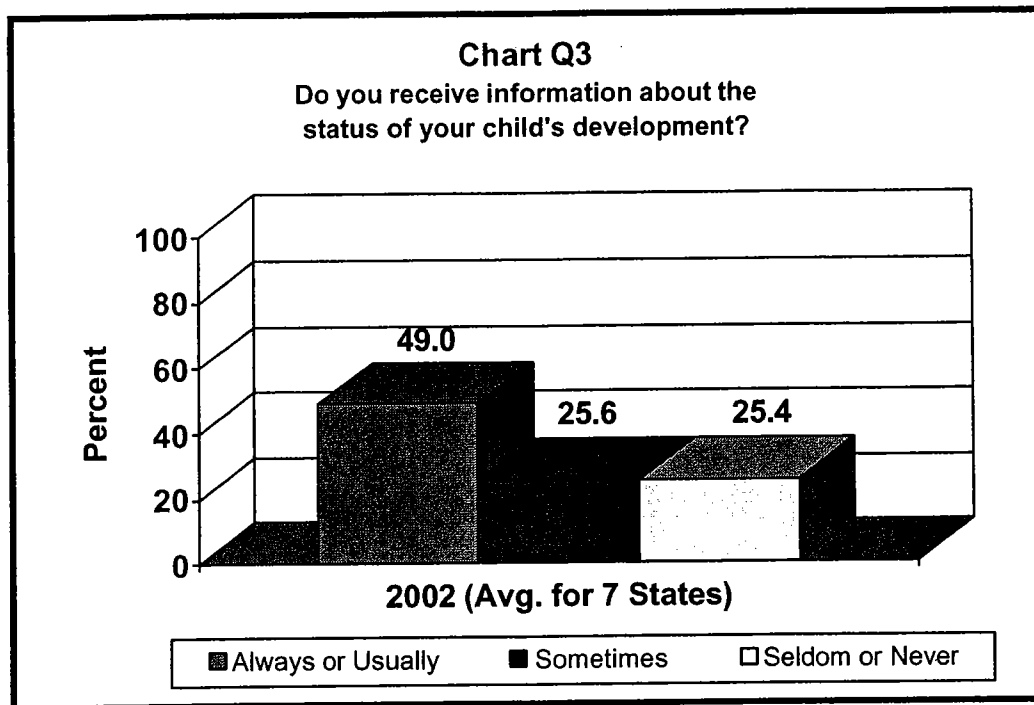


Table Q3
Do you receive information about the status of your child's development?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑↑↑	60.3	21.5	18.2	335
CA-RCOC	↓	42.1	29.6	28.3	805
MA		47.9	19.6	32.5	311
SC	↑	55.9	24.7	19.4	93
SD		51.6	30.7	17.6	153
WA	↓↓↓	33.3	21.7	45.1	415
WY		52.2	31.1	16.7	180
Total %		49.0	25.6	25.4	Total n = 2292
State Average		49.0	25.6	25.4	Total n = 2292

- ♦ Among those who receive this information, 62% found it easy to understand, and the remaining 38% found the information, at least sometimes, difficult to understand.

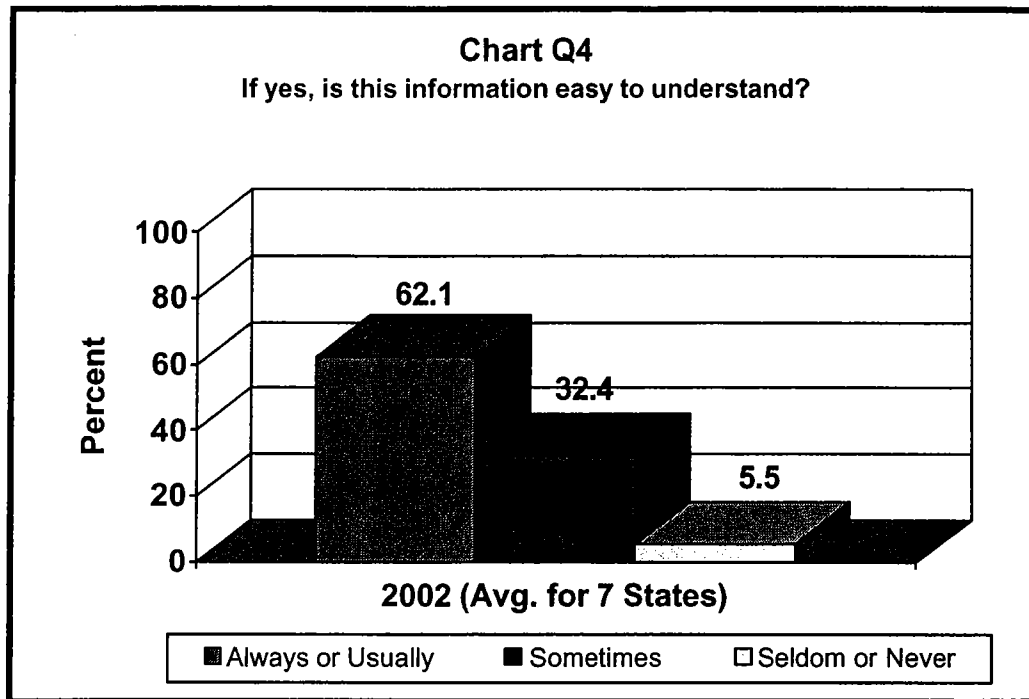


Table Q4
If yes, is this information easy to understand?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑↑	72.6	22.9	4.5	292
CA-RCOC		62.1	31.0	6.9	642
MA		65.5	30.7	3.8	238
SC		62.8	30.2	7.0	86
SD		62.2	34.1	3.7	135
WA	↓↓	52.1	38.2	9.7	288
WY		57.3	39.5	3.2	157
Total %		62.1	32.4	5.5	Total = 1598
State Average		62.1	32.4	5.5	Total = 1598

- ♦ Half of respondents (48%) stated they got enough information to help them participate in planning, however the other half (52%) indicated they only sometimes or seldom had enough information.

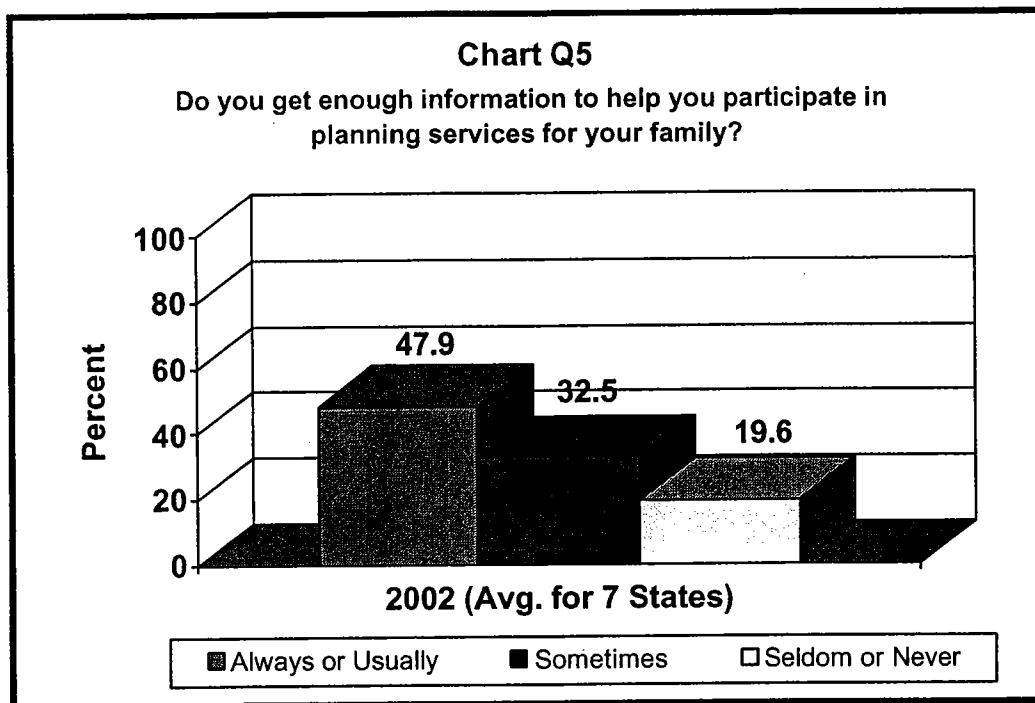


Table Q5

Do you get enough information to help you participate in planning services for your family?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		49.2	31.4	19.4	325
CA-RCOC		44.4	34.5	21.0	822
MA	↓↓	31.5	37.0	31.5	324
SC	↑↑	60.0	26.3	13.7	95
SD	↑↑	61.1	30.6	8.3	157
WA	↓↓	32.4	35.2	32.4	426
WY	↑	56.7	32.6	10.7	178
Total %		43.8	33.8	22.4	Total n = 2,437
State Average		47.9	32.5	19.6	Total n = 2,437

- ◆ Nearly three-quarters (72%) of respondents, on average across states, indicated that they typically help in developing their family member's service plan.

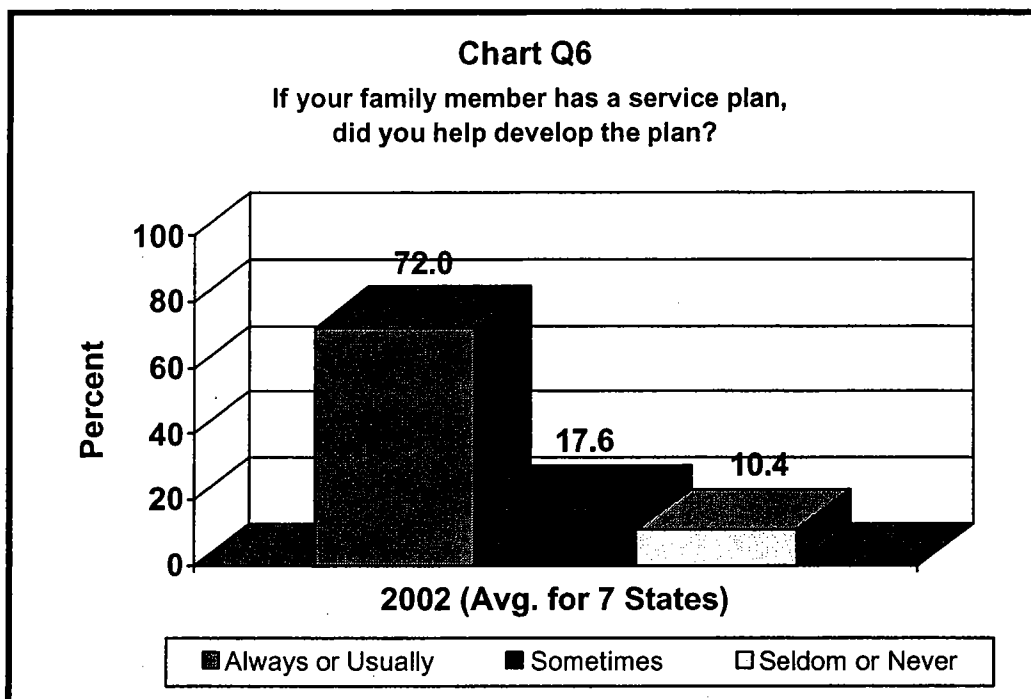


Table Q6
If your family member has a service plan, did you help develop the plan?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		74.6	17.3	8.1	260
CA-RCOC	↓	66.6	20.0	13.4	640
MA	↓↓	61.4	18.6	20.0	210
SC		67.8	23.0	9.2	87
SD	↑	79.3	17.2	3.4	145
WA	↓	64.6	18.2	17.2	291
WY	↑↑	89.6	9.2	1.2	163
Total		70.0	18.1	11.9	1,753
State Average		72.0	17.6	10.4	1,753

- ♦ Of those families with a service plan, 72% stated that the plan included things important to the respondent. Over one quarter of respondents (28%) indicated that the plan only sometimes, seldom or never included things important to them. South Dakota had notably higher results, with 82% of respondents stating the plan reflected goals important to them.

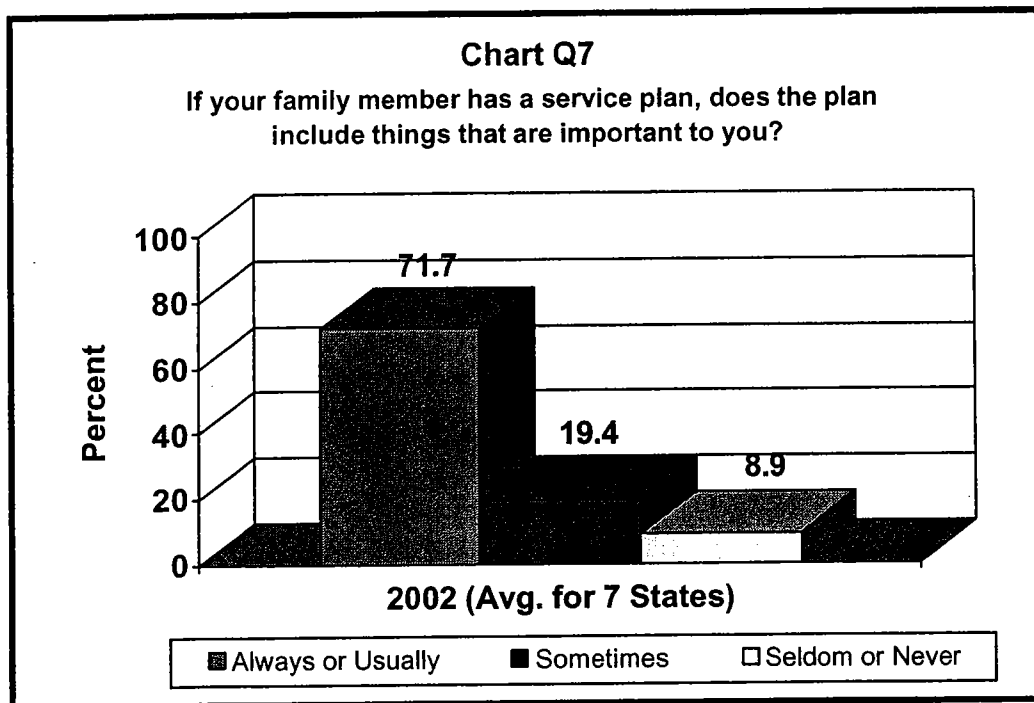


Table Q7

If your family member has a service plan, does the plan include things that are important to you?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		73.4	20.2	6.5	263
CA-RCOC	↓↓	61.0	25.8	13.1	616
MA		67.2	17.6	15.2	204
SC		73.0	15.7	11.2	89
SD	↑↑	81.8	14.7	3.5	143
WA	↓↓	60.4	28.3	11.3	293
WY	↑↑	85.2	13.6	1.2	162
Total		68.0	21.9	10.1	1,777
State Average		71.7	19.4	8.9	1,777

- ♦ Across states, over half (57%) indicated that planning staff would help them figure out the supports they needed. However, a large percentage (43%) stated that this was only sometimes or even seldom the case.

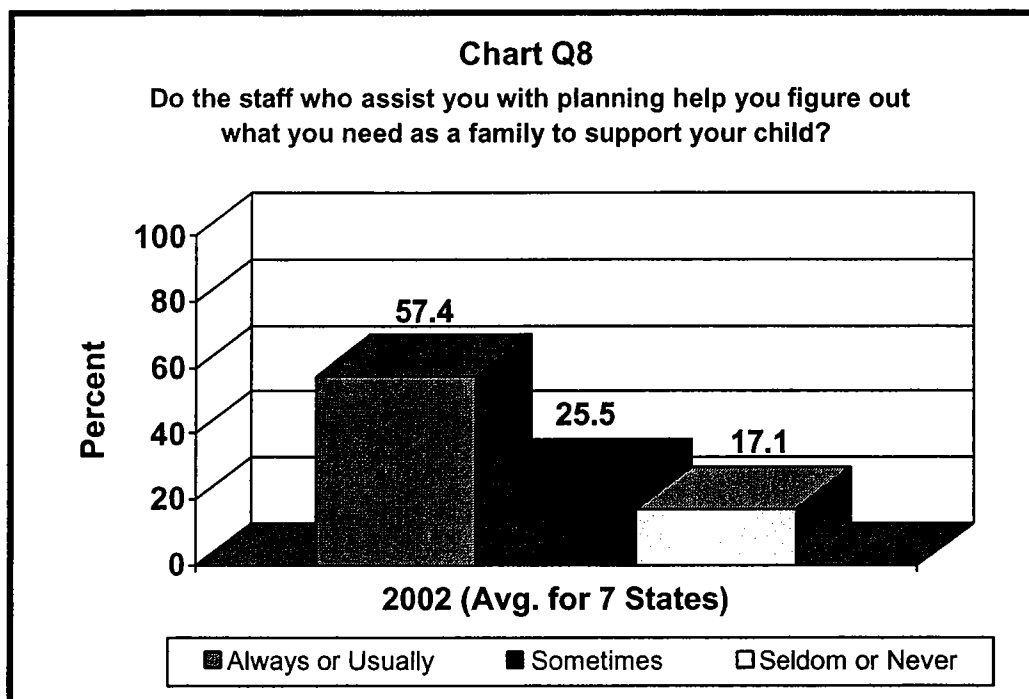


Table Q8

Do the staff who assist you with planning help you figure out what you need as a family to support your child?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		60.3	24.0	15.8	292
CA-RCOC	↓↓↓	41.3	34.6	24.1	818
MA	↓↓↓	45.1	28.5	26.4	235
SC	↑↑↑	68.5	18.5	13.0	92
SD	↑↑↑	75.3	18.0	6.7	150
WA	↓↓↓	43.8	31.0	25.3	352
WY	↑↑↑	67.8	23.6	8.6	174
Total %		50.5	29.1	20.4	Total n = 2,113
State Average		57.4	25.5	17.1	Total n = 2,113

- ♦ Across states, approximately three-quarters (77%) of respondents felt that staff respect their choices and opinions.

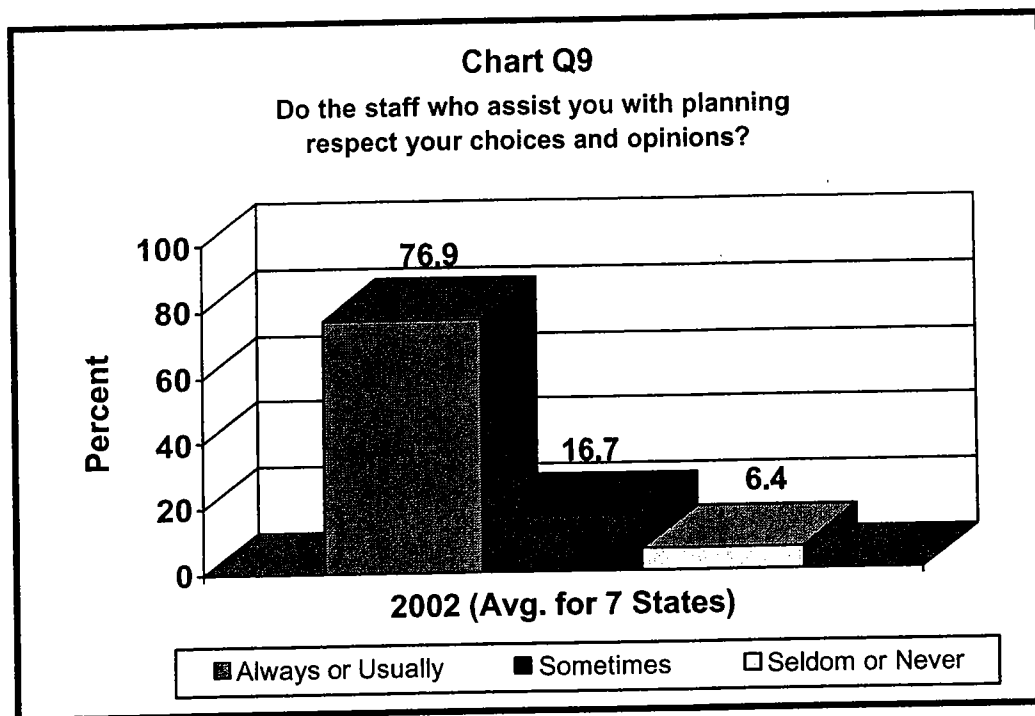


Table Q9
Do the staff who assist you with planning respect your choices and opinions?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		80.5	14.6	4.9	287
CA-RCOC		73.5	19.2	7.3	791
MA	↓	71.1	17.1	11.8	228
SC		78.0	17.6	4.4	91
SD	↑	83.1	13.6	3.2	154
WA	↓	70.6	19.8	9.6	344
WY		81.5	15.0	3.5	173
Total %		75.3	17.6	7.1	Total = 2038
State Average		76.9	16.7	6.4	Total = 2038

- ♦ Only one-third (36%) of respondents indicated that planning staff discussed with them the public benefits that may or may not be available to them. Another quarter occasionally received this information, while 39% indicated that planning staff did not relay this information to them. Results were fairly consistent across states, with the exception of South Carolina (in which approximately half of families did discuss public benefits) and Massachusetts (where fewer than one-fourth of families had these discussions).

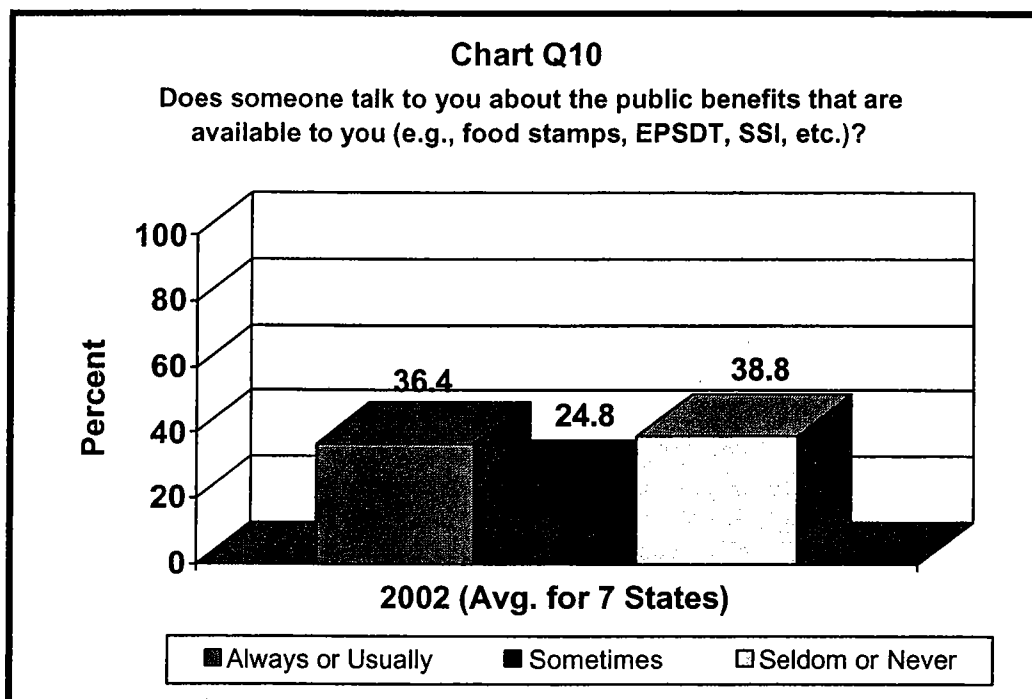


Table Q10

Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI, etc.)?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		37.0	20.8	42.2	289
CA-RCOC		34.7	26.9	38.4	796
MA	↓↓↓	22.3	22.6	55.1	283
SC	↑↑↑	52.1	22.3	25.5	94
SD	↑	46.3	32.9	20.8	149
WA	↓	27.0	22.9	50.1	397
WY		35.2	25.5	39.4	165
Total %		36.4	24.8	38.8	Total = 2,173
State Average		36.4	24.8	38.8	Total = 2,173

- ♦ Among all respondents, 87% felt that agency staff were generally respectful and courteous. Across all states, these results were fairly consistent.

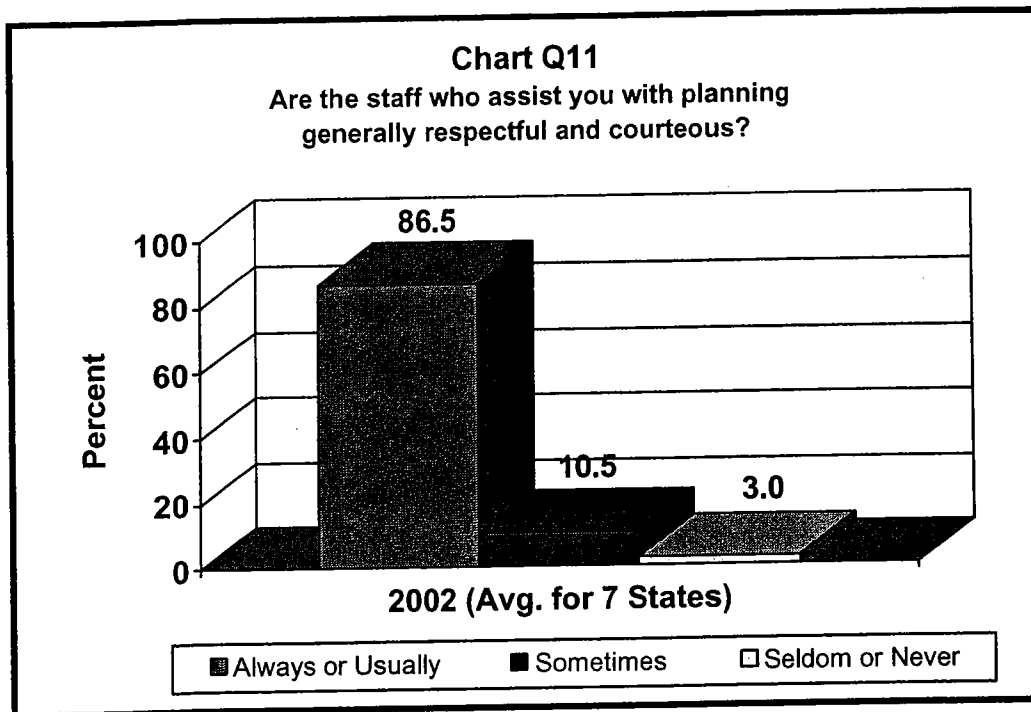


Table Q11
Are the staff who assist you with planning generally respectful and courteous?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		86.6	10.8	2.5	314
CA-RCOC		84.3	12.9	2.7	875
MA		83.5	10.2	6.3	255
SC		86.0	9.7	4.3	93
SD	↑	92.6	6.2	1.2	162
WA		83.0	15.0	2.0	400
WY		89.3	9.0	1.7	178
Total %		85.4	11.8	2.8	Total = 1,277
State Average		86.5	10.5	3.0	Total = 1,277

- ♦ Among all respondents, 67% felt that agency staff were generally effective.

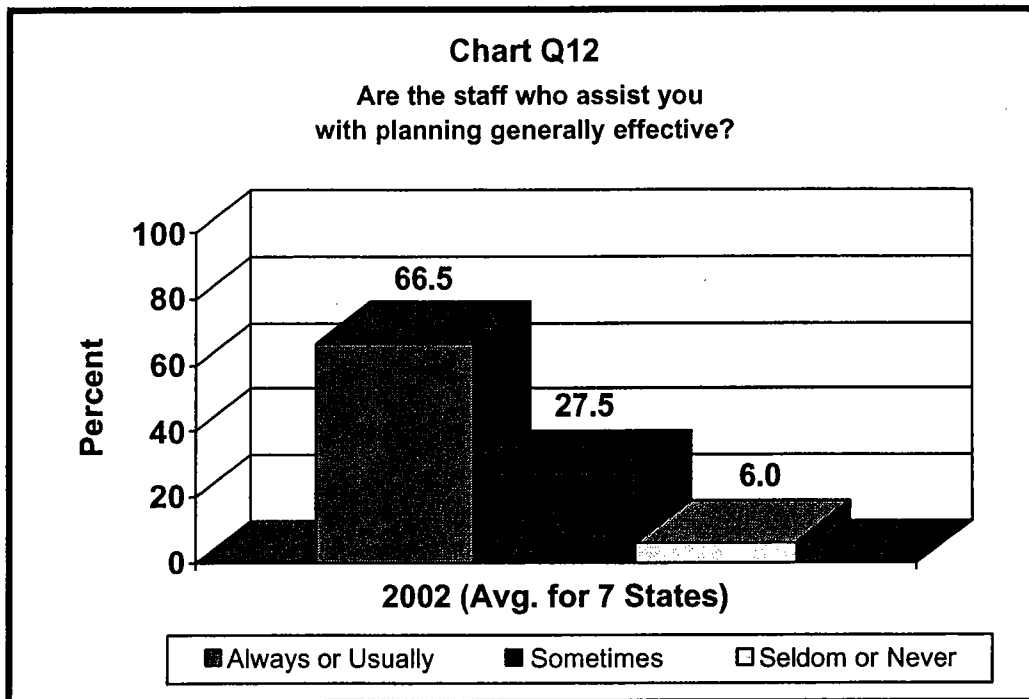


Table Q12
Are the staff who assist you with planning generally effective?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		66.0	27.8	6.2	306
CA-RCOC	↓	59.2	33.1	7.6	839
MA	↓↓	54.5	35.6	9.9	253
SC	↑	72.5	22.0	5.5	91
SD	↑↑	84.0	14.8	1.2	162
WA	↓	57.4	34.5	8.2	380
WY	↑	71.9	24.7	3.4	178
Total %		62.7	30.4	6.9	Total = 2,215
State Average		66.5	27.5	6.0	Total = 2,215

- ♦ Across all states, fewer than three-quarters (71%) of respondents indicated they could typically contact staff when desired.

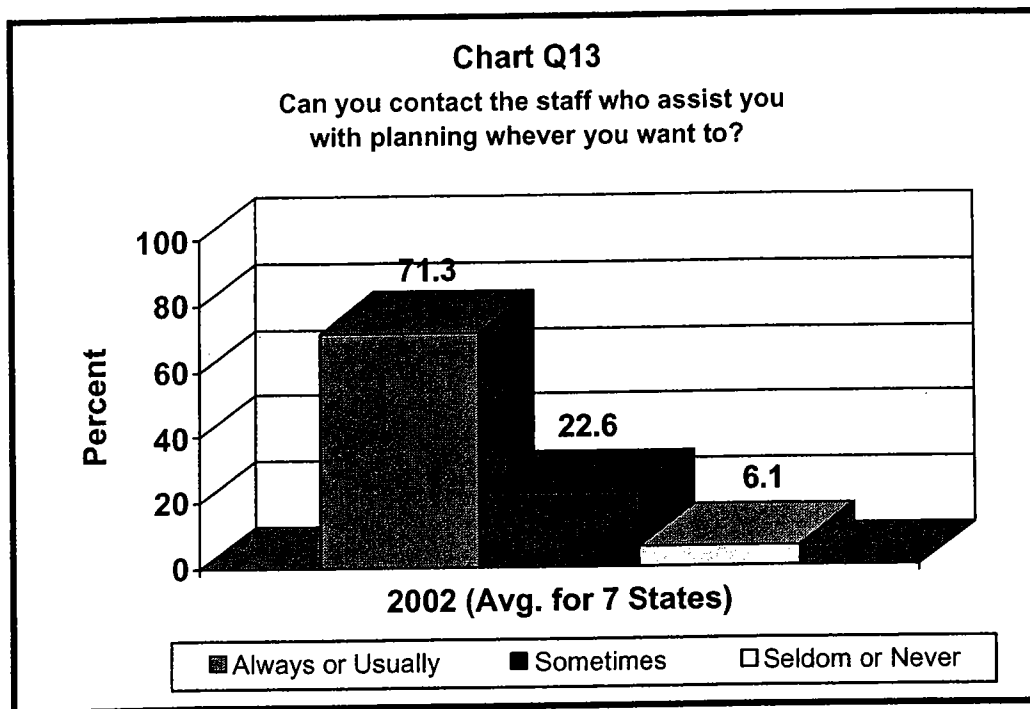


Table Q13
Can you contact the staff who assist you with planning whenever you want to?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		69.5	23.4	7.1	308
CA-RCOC		68.8	25.9	5.3	852
MA	↓	61.6	30.2	8.2	255
SC		75.8	17.6	6.6	91
SD	↑↑	84.0	13.6	2.5	162
WA	↓↓	59.4	31.0	9.6	394
WY	↑	80.2	16.4	3.4	177
Total %		68.7	25.0	6.3	1734
State Average		71.3	22.6	6.1	1734

Access to and Delivery of Services and Supports

- Overall, 68% of families stated their service coordinator helped them get needed supports when asked. Twenty-five percent said this happened sometimes, and 7% indicated that their service coordinator was rarely helpful in getting the assistance needed.

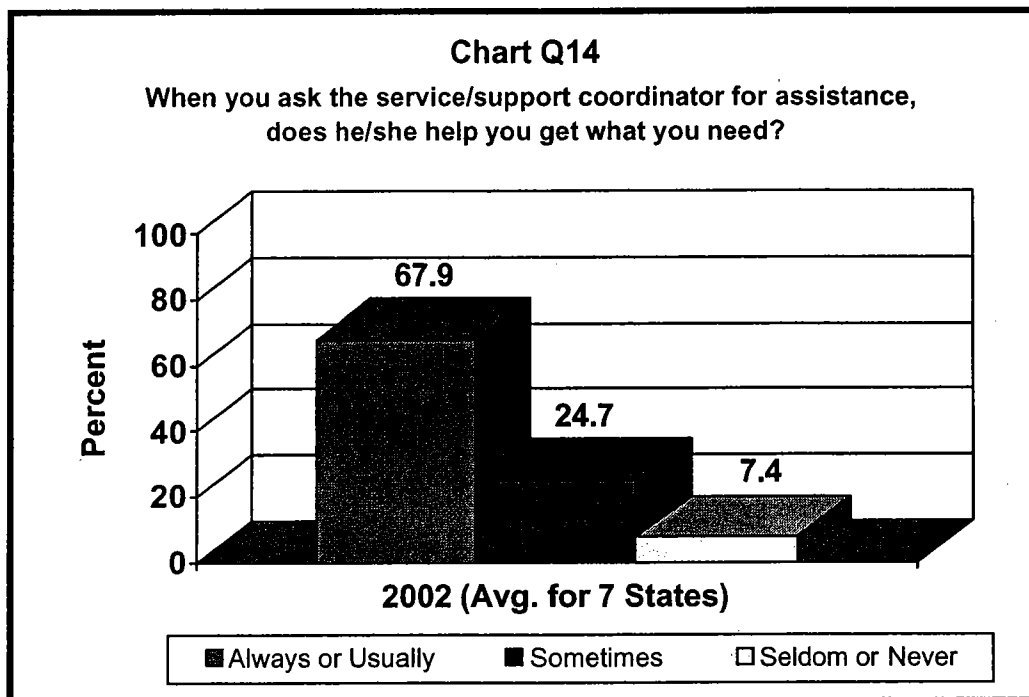


Table Q14
When you ask the service/support coordinator for assistance, does he/she help you get what you need?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		68.0	25.1	6.9	334
CA-RCOC	↓ ↓	47.0	35.0	18.0	734
MA	↓ ↓	57.5	34.0	8.4	285
SC		70.4	19.4	10.2	98
SD	↑ ↑	89.0	9.8	1.2	163
WA		64.5	29.9	5.7	442
WY	↑ ↑	79.2	19.7	1.1	178
Total %		67.9	24.7	7.4	Total n = 2222
State Average		67.9	24.7	7.4	1061

- ♦ Fifty-four percent of respondents said they always or usually get the services and supports needed. Thirty-six percent got needed supports some of the time, and the remaining 10% seldom or never received needed supports.

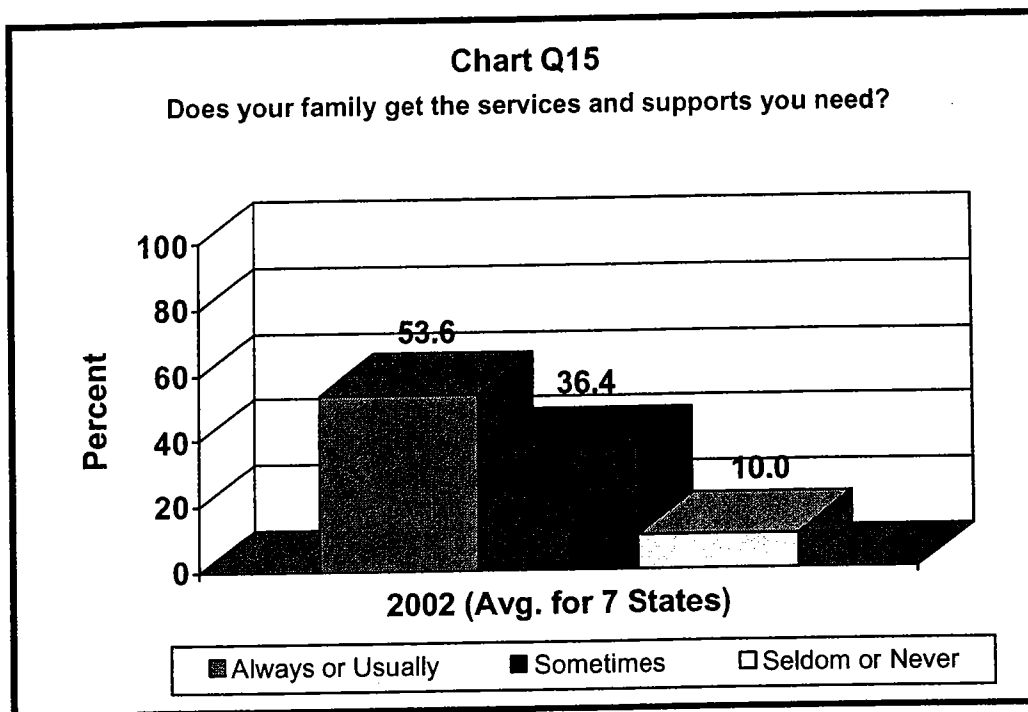


Table Q15
Does your family get the services and supports you need?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		56.3	34.4	9.3	334
CA-RCOC		49.0	40.0	11.1	823
MA	↓↓	34.4	45.4	20.2	317
SC	↑	60.8	26.8	12.4	97
SD	↑↑	75.0	23.2	1.8	164
WA	↓↓	41.9	46.0	12.1	446
WY		58.0	39.2	2.8	181
Total		49.7	39.3	11.0	Total = 2362
State Average		53.6	36.4	10.0	Total =

- ♦ Among all respondents, about half (51%) said that the supports received met their families' needs, although this varied quite a bit from state to state. Another 38% said that the supports sometimes met their needs, while the remaining 11% seldom or never felt the supports offered met their family's needs.

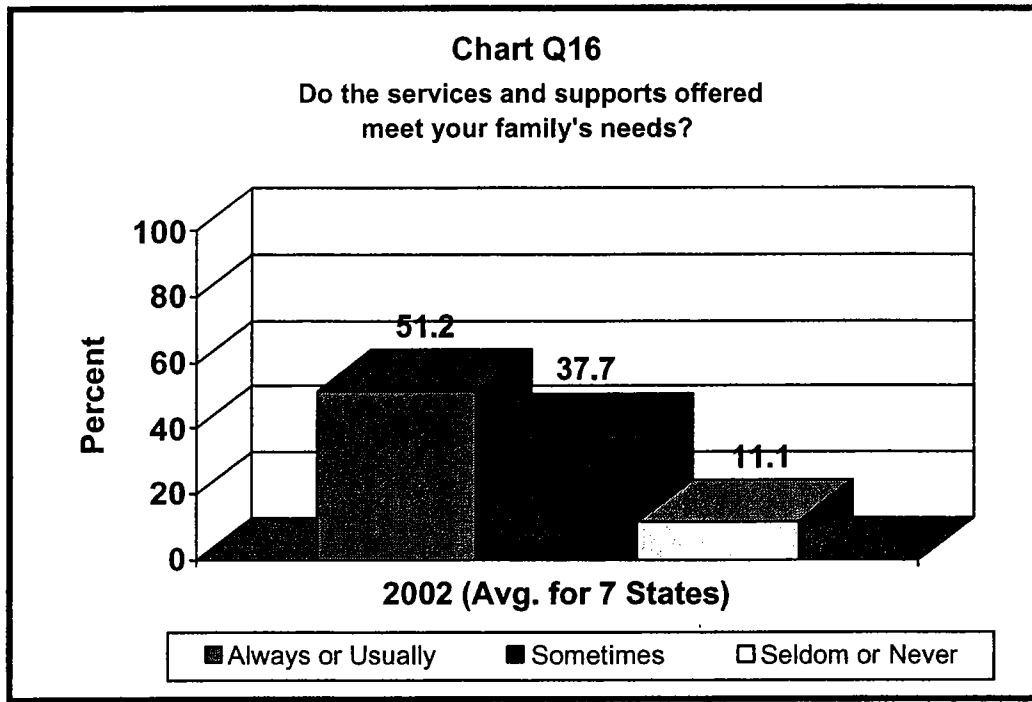


Table Q16
Do the services and supports offered meet your family's needs?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		52.6	38.5	8.9	327
CA-RCOC	↕	44.0	41.3	14.7	797
MA	↕↕	35.2	42.2	22.5	315
SC	↑	58.2	31.6	10.2	98
SD	↑↑	70.8	26.2	3.0	168
WA	↕↕	36.7	48.8	14.5	441
WY	↑	61.1	35.0	3.9	180
Total		46.5	40.5	13.0	2,281
State Average		51.2	37.7	11.1	Total

- ♦ For less than half of families (46%), supports were always or usually available when needed. However, almost as many families indicated that supports were only sometimes available (41%), or seldom/never available (12%) when needed.

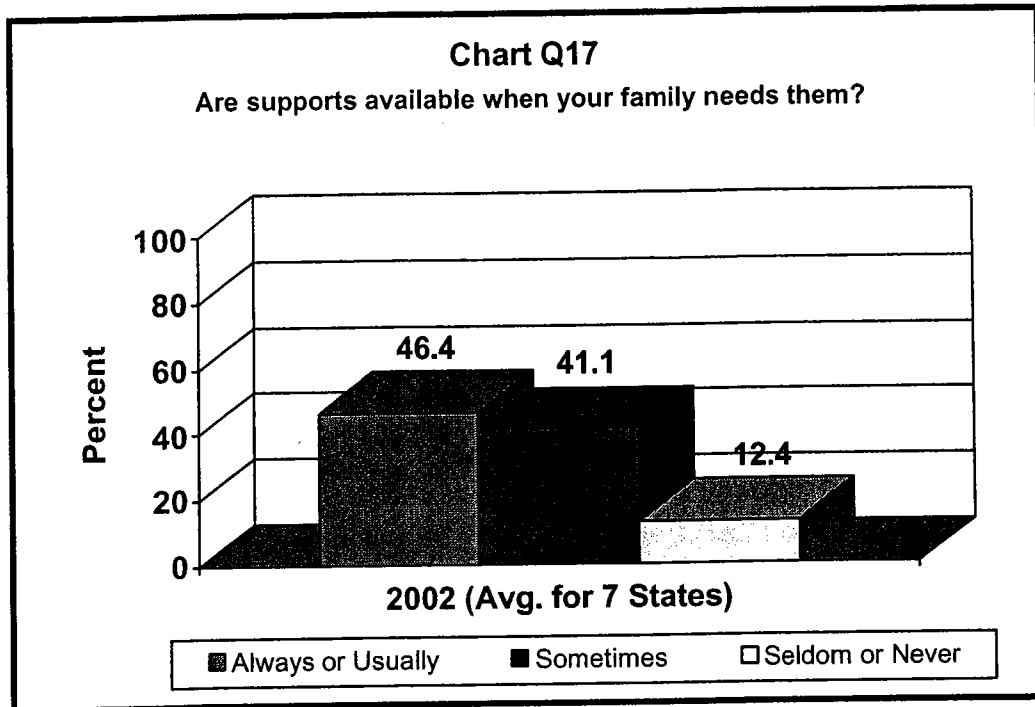


Table Q17
Are supports available when your family needs them?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		46.7	41.7	11.5	321
CA-RCOC		43.1	42.5	14.4	764
MA	↓↓↓	31.2	46.7	22.1	317
SC	↑	54.8	33.3	11.8	93
SD	↑↑↑	66.5	29.9	3.7	164
WA	↓↓↓	35.6	47.6	16.8	435
WY		47.2	46.1	6.7	178
Total %		45.0	43.0	12.0	Total = 2,272
State Average		46.4	41.1	12.4	Total = 2,272

- Eighty-five percent of respondents stated that families in their area at least occasionally asked for different types of supports than the ones that were currently being offered.

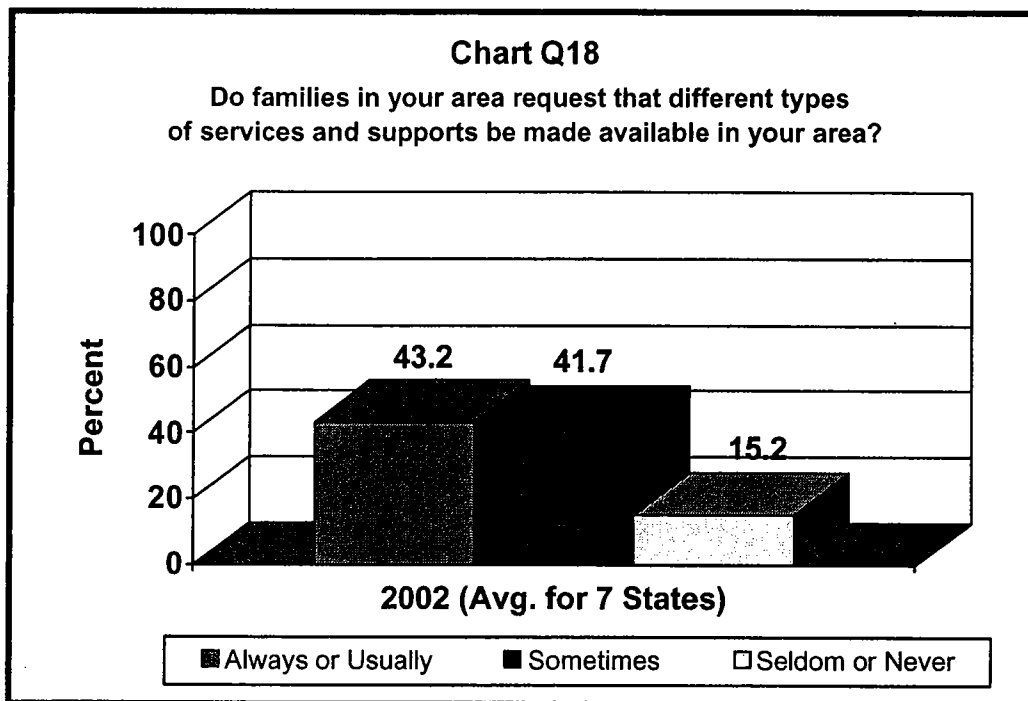


Table Q18

Do families in your area request that different types of services and supports be made available in your area?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	50.8	34.6	14.6	130
CA-RCOC	↑	48.7	37.0	14.3	446
MA	↓↓	30.8	53.1	16.1	143
SC	↑	49.0	28.6	22.4	49
SD		43.5	43.5	13.0	46
WA		39.1	43.8	17.2	169
WY		40.4	51.1	8.5	94
Total		43.2	41.7	15.2	507
State Average		43.2	41.7	15.2	507

- ♦ On the occasions when families did request different types of supports, 38% indicated that the state agency or provider agency was usually or always responsive to these requests.

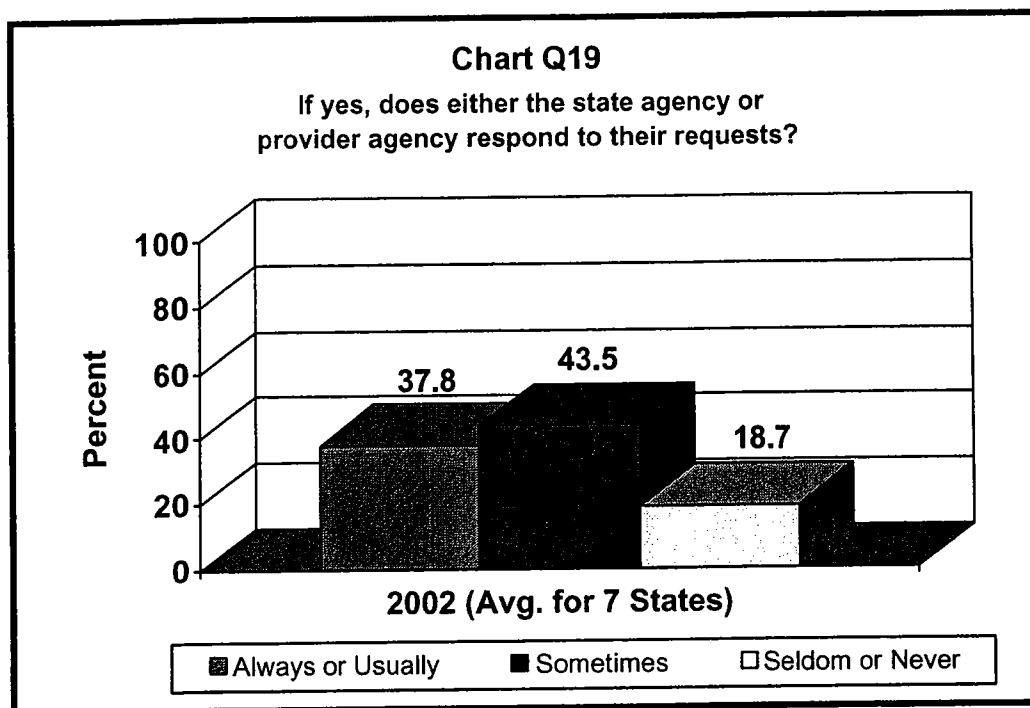


Table Q19
If yes, does either the state agency or provider agency respond to their requests?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		37.1	48.3	14.7	116
CA-RCOC	↓	30.6	39.1	30.3	271
MA		39.0	48.8	12.2	123
SC	↑	47.4	34.2	18.4	38
SD	↑↑	61.1	30.6	8.3	36
WA	↓↓	20.3	42.2	37.5	128
WY	↓	29.2	61.1	9.7	72
Total %		37.8	43.5	18.7	Total n = 764
State Average		37.8	43.5	18.7	Total n = 764

- ♦ About half (48%) of families who asked for assistance in an emergency or crisis did not consistently receive help right away.

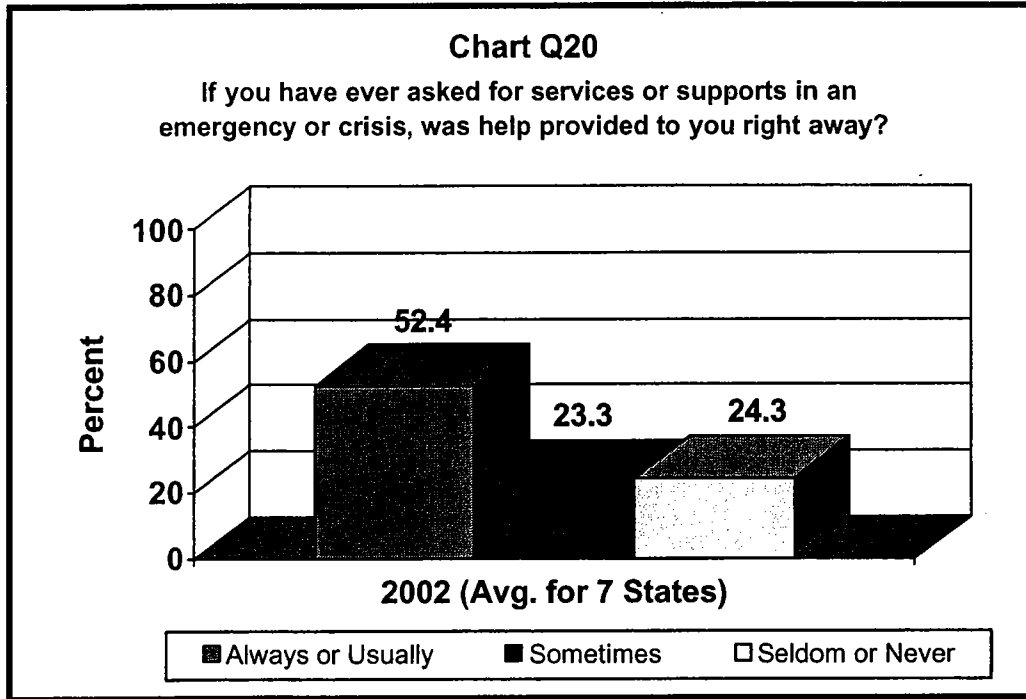


Table Q20

If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓	41.1	20.3	38.6	158
CA-RCOC		51.7	24.7	23.6	360
MA		53.1	19.4	27.5	160
SC	↑	57.9	24.6	17.5	57
SD	↑↑	74.7	16.5	8.8	91
WA	↓↓	35.4	26.9	37.7	212
WY		53.2	30.4	16.5	79
Total %		49.8	26.5	23.7	Total
State Average		52.4	23.3	24.3	Total

- ♦ Among respondents whose first language was not English, a slight majority (58%) indicated that staff or translators were available to speak with them in their preferred languages. Twenty-four percent indicated that staff/translators were sometimes available, and the remaining 17% stated that staff/translators who spoke in the families' preferred languages were not available.

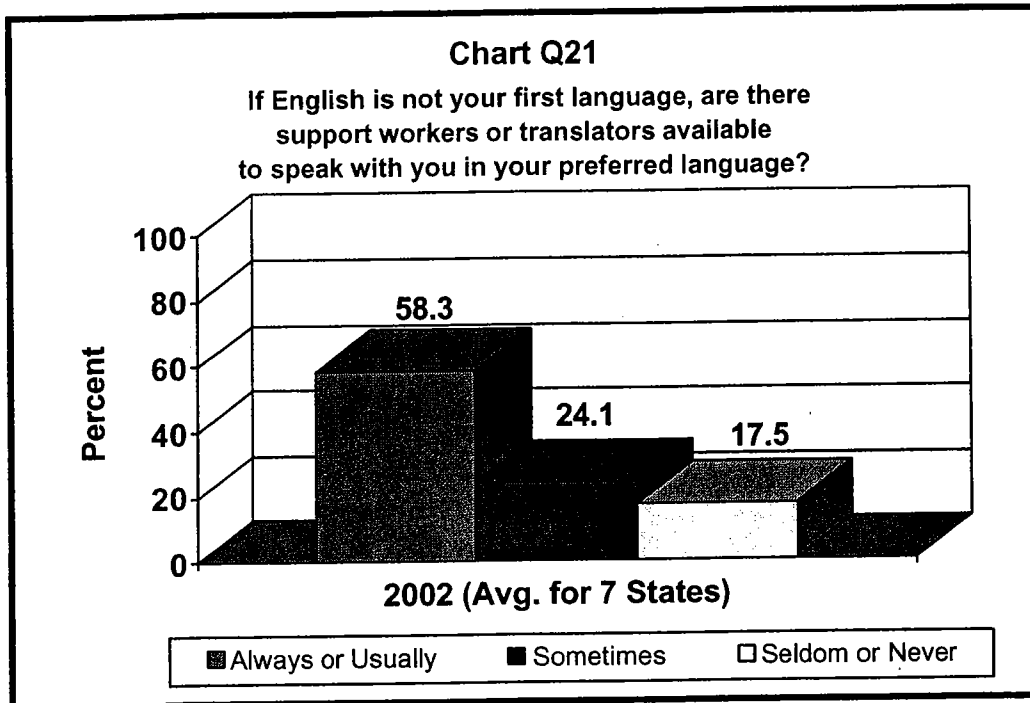


Table Q21

If English is not your first language, are there support workers or translators available to speak with you in your preferred language?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		61.5	21.5	16.9	65
CA-RCOC		53.6	22.4	24.0	250
MA		61.9	23.8	14.3	21
SC	↑↑↑	72.2	11.1	16.7	18
SD	↓	50.0	25.0	25.0	4
WA		59.1	25.0	15.9	44
WY	↓	50.0	40.0	10.0	10
Total %		56.5	22.6	20.9	Total = 412
State Average		58.3	24.1	17.5	Total = 412

- ♦ Among respondents who had children who did not speak English, or who used a different means to communicate (e.g., sign language, communication board), 40% of families said there were enough support staff regularly available who could communicate with their family member. The remaining 60%, however, said capable staff were only sometimes, seldom or never available.

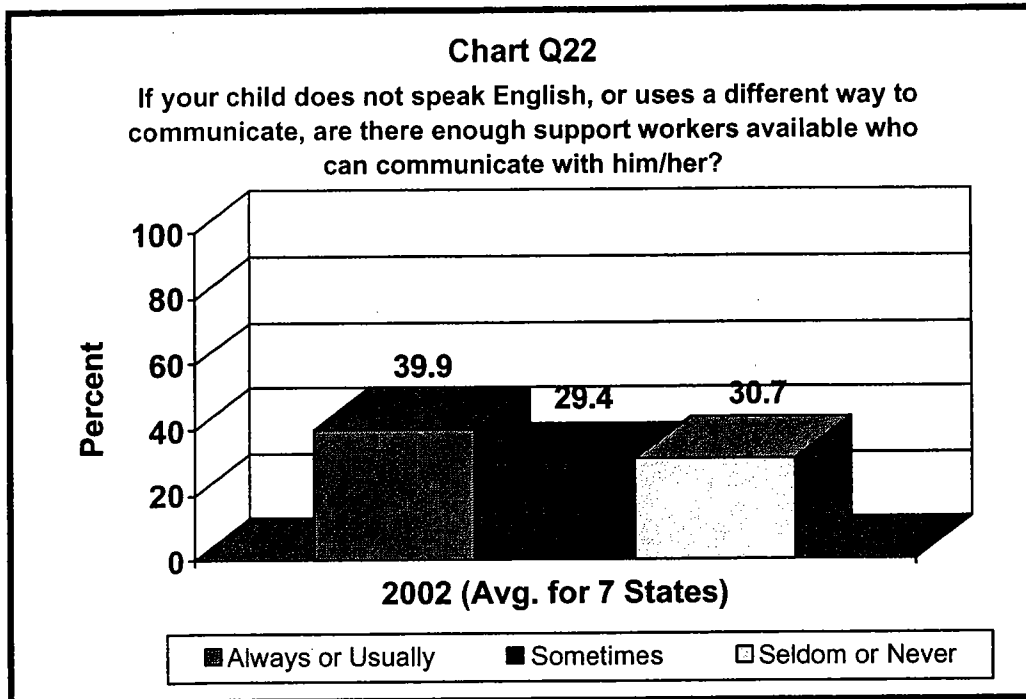


Table Q22

If your child does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		42.6	35.1	22.3	94
CA-RCOC	↑↑	74.4	16.4	9.2	379
MA	↓	30.2	28.6	41.3	63
SC	↑↑	58.8	0.0	41.2	17
SD	↓↓	21.6	45.9	32.4	37
WA	↓↓	17.6	36.8	45.6	68
WY	↓	34.1	43.2	22.7	44
Total %		39.9	29.4	30.7	Total = 768
State Average		39.9	29.4	30.7	Total = 768

- ♦ Slightly more than one-half of respondents (57%) felt their child had access to the special equipment or accommodations needed.

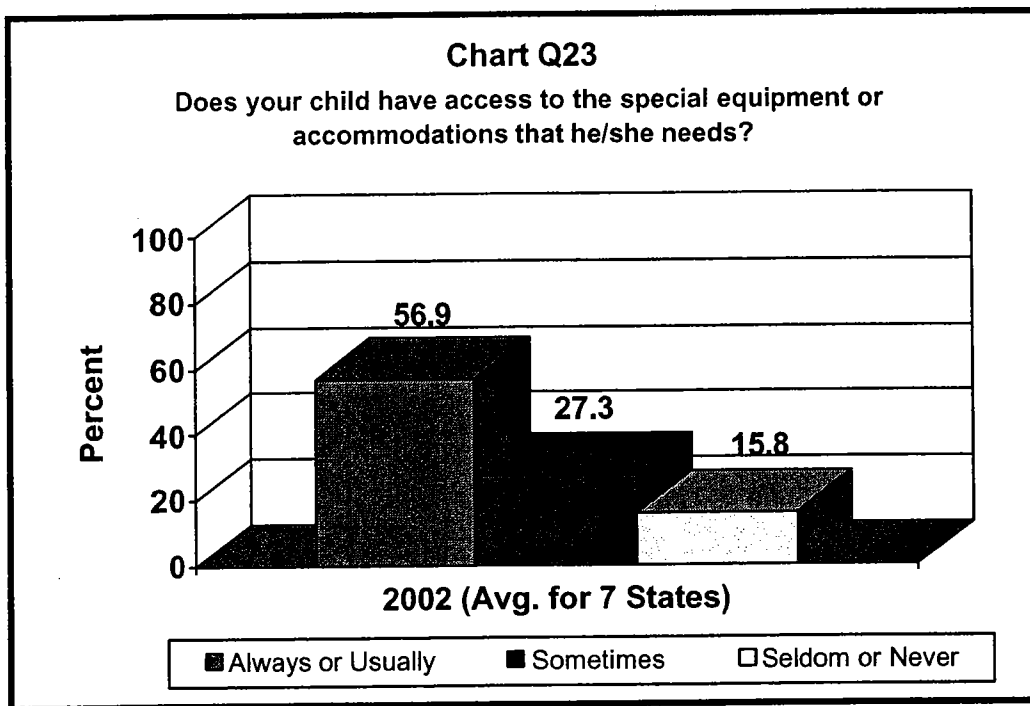


Table Q23

Does your child have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		57.5	25.7	16.8	167
CA-RCOC		55.5	26.1	18.4	364
MA	↓	48.3	32.4	19.3	176
SC		60.5	16.3	23.3	43
SD	↑↑↑	69.6	26.1	4.3	115
WA	↓↓↓	44.6	36.5	18.9	249
WY	↑	62.2	28.3	9.4	127
Total %		56.9	27.3	15.8	Total = 1211
State Average		56.9	27.3	15.8	Total = 7

- ♦ The vast majority of respondents (90%) felt that they had access to health services for their child.

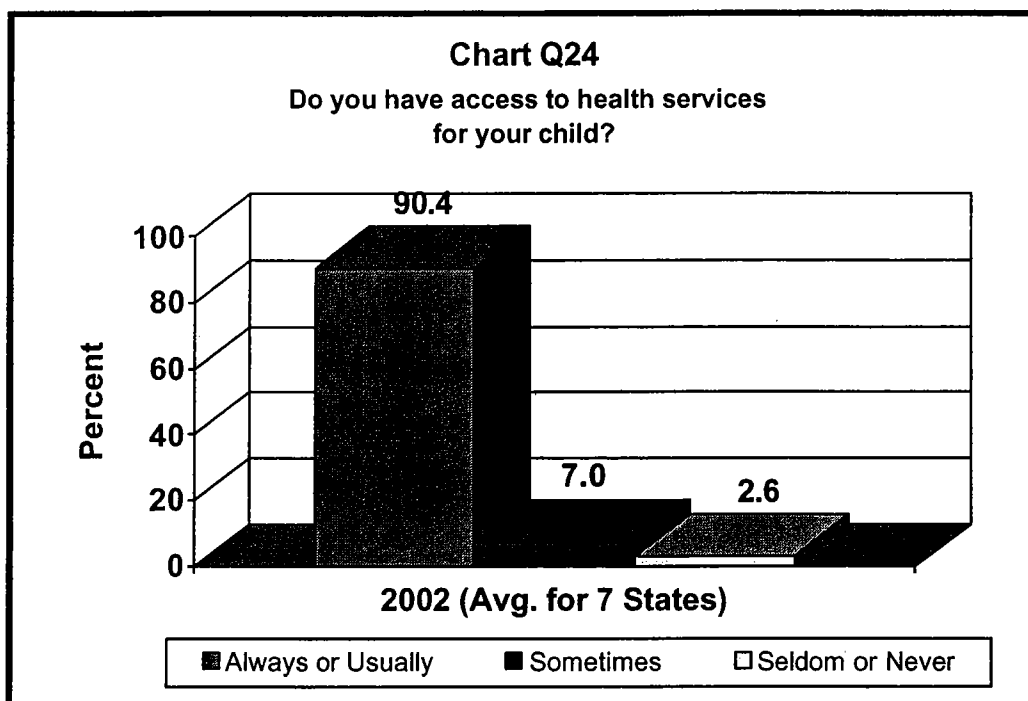


Table Q24
Do you have access to health services for your child?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		91.4	7.7	0.9	336
CA-RCOC	↓	81.0	8.3	10.7	674
MA		91.3	6.5	2.3	355
SC		88.8	9.2	2.0	98
SD	↑	96.5	3.5	0.0	171
WA		90.3	7.5	2.2	455
WY		93.5	6.5	0.0	184
Total %		88.5	7.3	4.2	Total = 2227
State Average		90.4	7.0	2.6	Total = 2227

- ♦ Slightly fewer families (87%) felt they had access to appropriate dental services for their family member. These results were consistent across states.

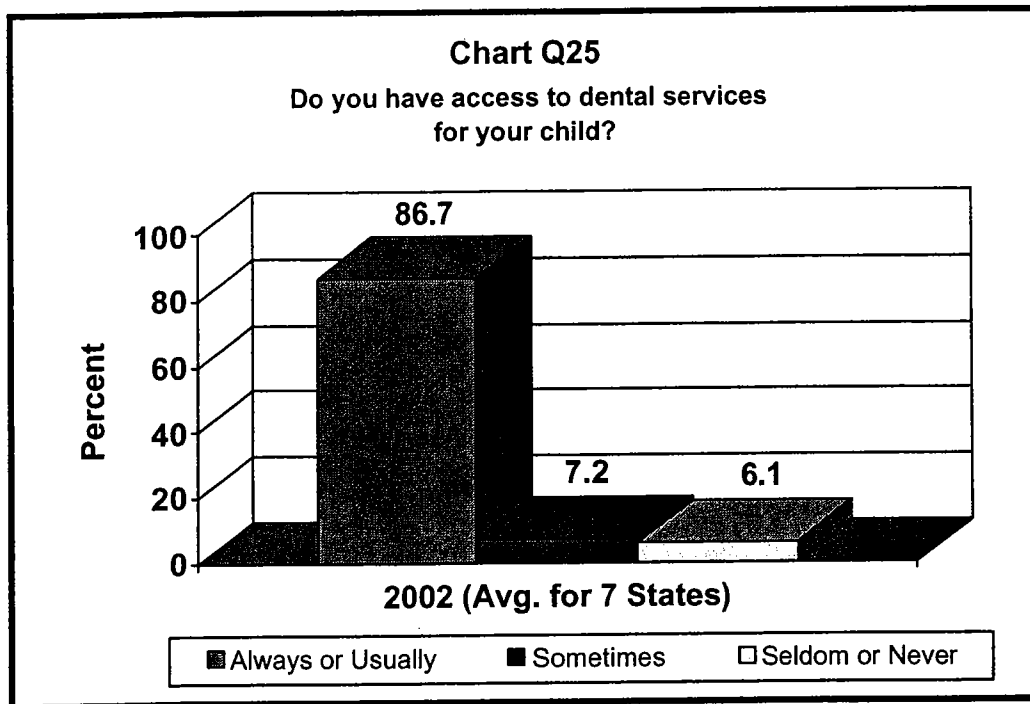


Table Q25
Do you have access to dental services for your child?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	87.1	7.3	5.7	317
CA-RCOC	83.1	6.3	10.6	780
MA	86.8	5.9	7.3	356
SC	90.5	6.3	3.2	95
SD	88.7	8.8	2.5	159
WA	85.5	6.9	7.6	448
WY	85.2	8.8	6.0	182
Total %	85.5	6.8	7.7	Total n
State Average	86.7	7.2	6.1	Total n

- ◆ Nearly all respondents (91%) felt they had access to necessary medications for their child with a disability.

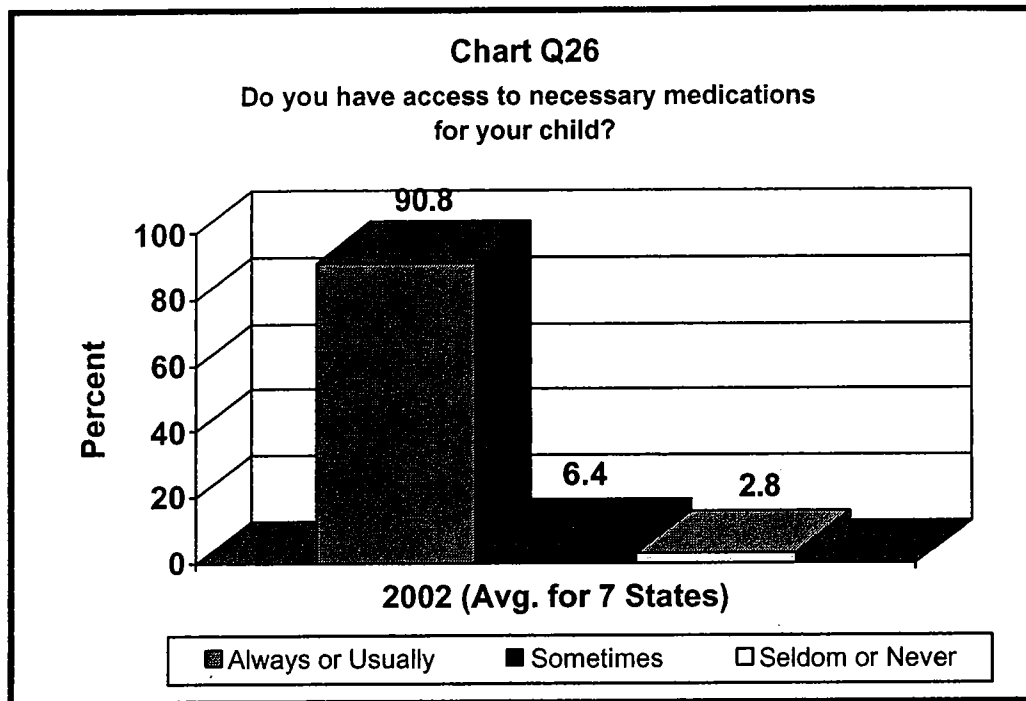


Table Q26
Do you have access to necessary medications for your child?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		88.0	10.4	1.6	316
CA-RCOC	↓	82.4	10.1	7.5	783
MA		91.7	5.9	2.4	337
SC		89.7	4.1	6.2	97
SD	↑	98.2	1.8	0.0	165
WA		91.0	6.9	2.1	435
WY		94.3	5.7	0.0	174
Total %		88.5	7.8	3.6	Total n = 2,407
State Average		90.8	6.4	2.8	Total n = 2,407

- ♦ Three-quarters of respondents (76%) indicated that frequent changes in support staff were a problem for their family at least some of the time.

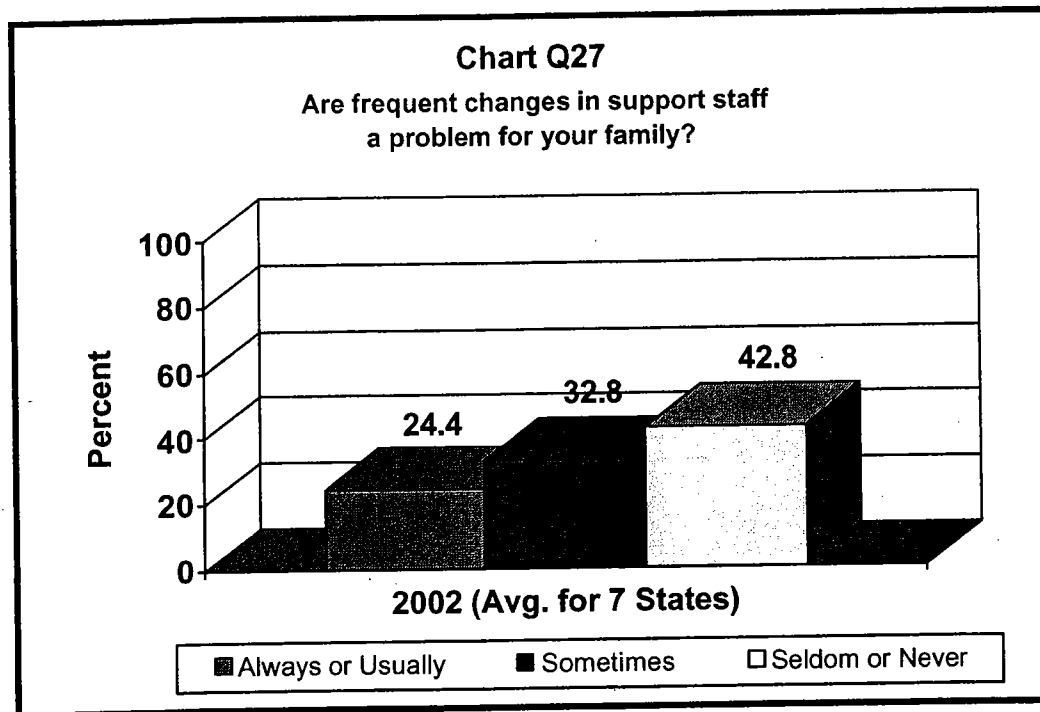


Table Q27
Are frequent changes in support staff a problem for your family?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		24.2	34.7	41.1	285
CA-RCOC	↓↓	47.3	28.2	24.4	712
MA		19.9	34.7	45.4	251
SC	↑	25.6	25.6	48.7	78
SD	↑↑	11.8	31.5	56.7	127
WA		23.8	34.8	41.5	328
WY		18.3	40.2	41.5	164
Total %		30.8	32.2	37.0	Total = 1917
State Average		24.4	32.8	42.8	Total = 1917

- ♦ The vast majority of families (84%) felt that support staff, in general, were respectful and courteous.

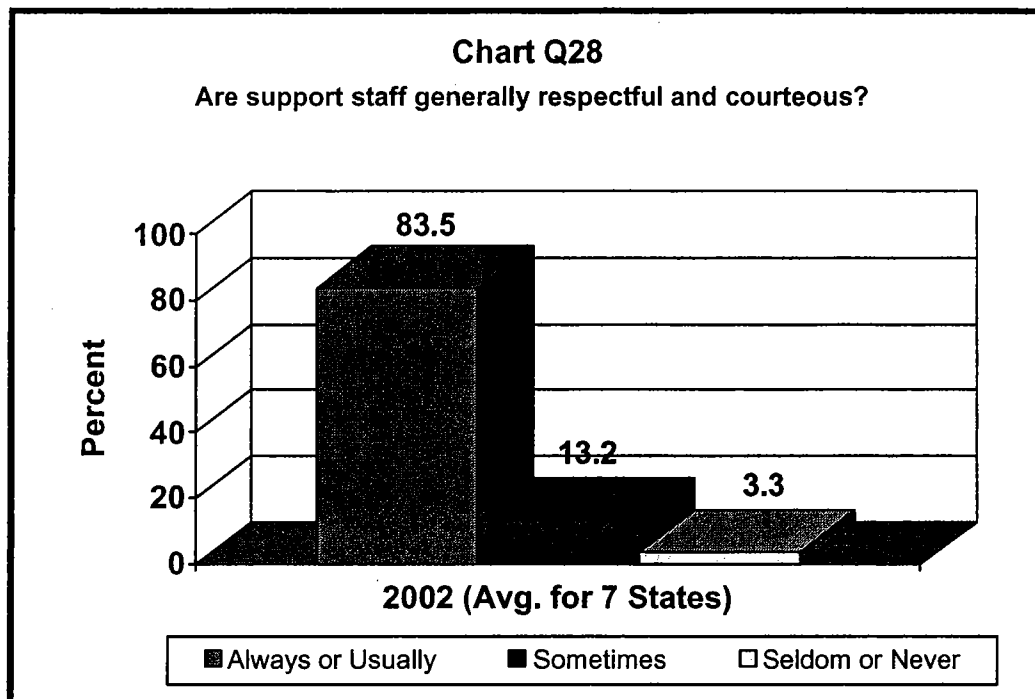


Table Q28
Are support staff generally respectful and courteous?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		85.5	13.0	1.5	330
CA-RCOC	↓↓	64.1	23.1	12.8	713
MA		86.3	11.9	1.8	278
SC		82.1	14.7	3.2	95
SD	↑↑	93.7	5.0	1.3	159
WA		86.6	12.3	1.1	357
WY		86.4	12.4	1.1	177
Total %		79.1	15.9	5.0	Total =2,410
State Average		83.5	13.2	3.3	Total =2,410

Choice and Control

- ♦ Across the states, on average, 52% of respondents chose the agencies or providers who work with their families. In Wyoming, this percentage was considerably higher, with 78% or more of families choosing their service providers. In South Dakota, Arizona and Orange County, California, considerably fewer families chose their providers/agencies.

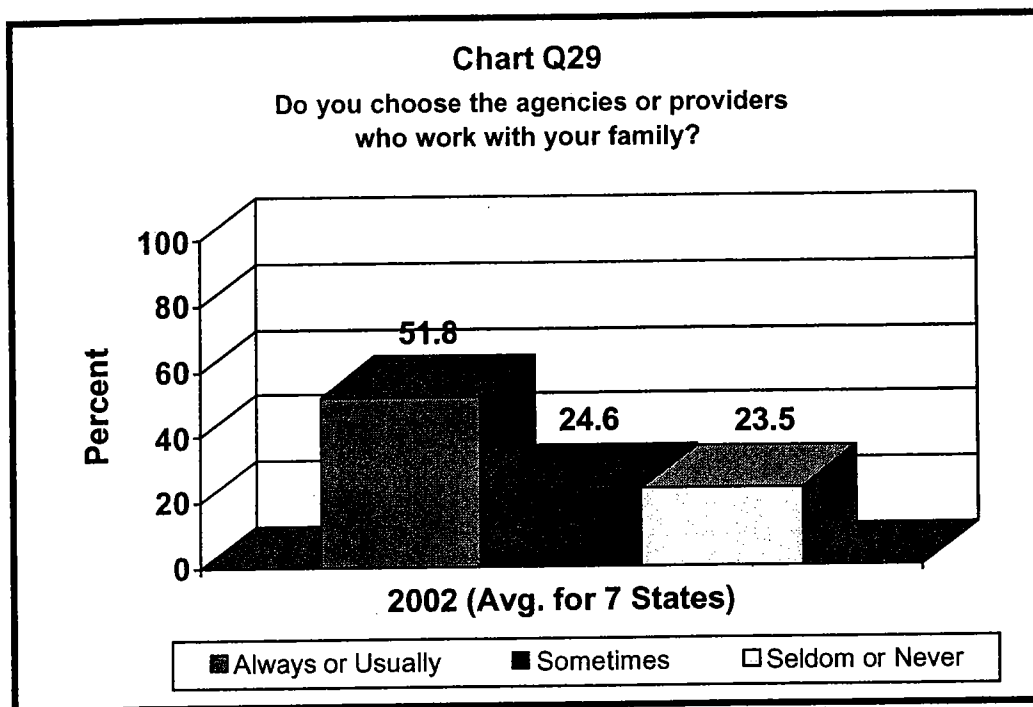


Table Q29
Do you choose the agencies or providers who work with your family?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓↓	39.6	30.7	29.7	313
CA-RCOC	↓↓↓	35.4	28.5	36.2	622
MA		53.8	24.7	21.5	279
SC		52.9	22.4	24.7	85
SD	↓↓↓	41.5	27.9	30.6	147
WA	↑	61.6	19.2	19.2	406
WY	↑↑↑	78.1	19.1	2.7	183
Total		48.8	25.8	25.5	Total = 2033
State Average		51.8	24.6	23.5	Total

- ♦ While 52% of respondents typically chose their family's provider agency, only 42% (on average) typically chose the support workers who worked directly with their family. Once again, the results were considerably higher in Wyoming.

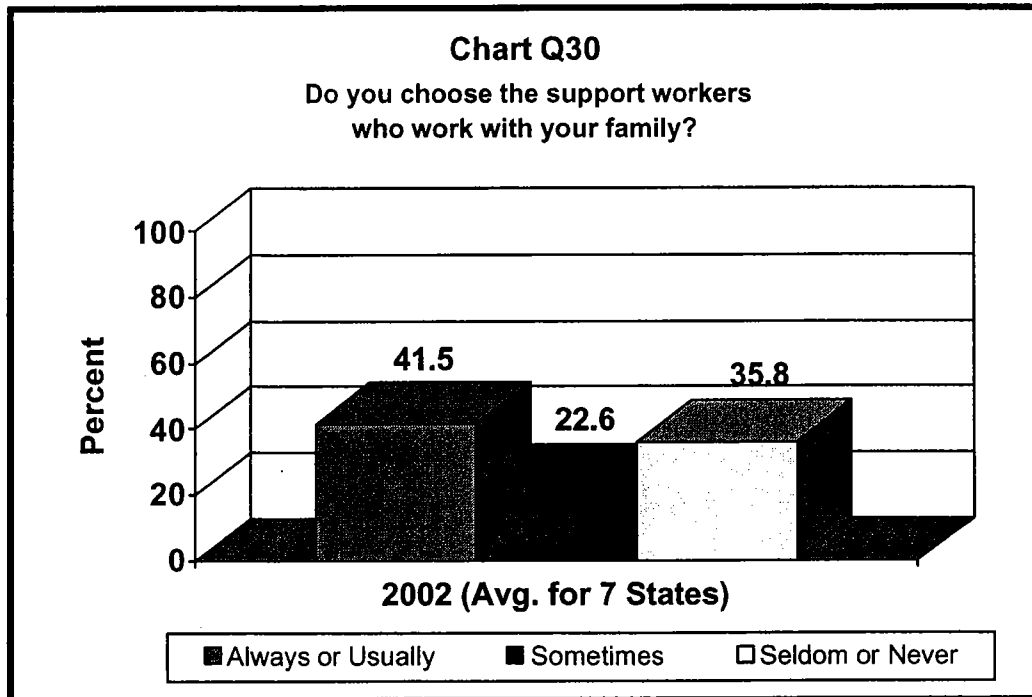


Table Q30
Do you choose the support workers who work with your family?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓	31.9	24.6	43.5	285
CA-RCOC	↓↓	25.2	20.4	54.5	604
MA		41.0	27.6	31.3	268
SC	↑	46.8	21.5	31.6	79
SD	↓↓	30.7	26.3	43.1	137
WA		38.5	19.6	41.9	358
WY	↑↑	76.7	18.3	5.0	180
Total %		37.0	22.1	40.9	Total n = 1951
State Average		41.5	22.6	35.8	Total n =

- ♦ Among all respondents, about one-third (37%) had control or input over the hiring and management of their support staff, and an additional 16% indicated they had this control sometimes. Forty-seven percent, however, had little or no input/control over the hiring or management of their family's support staff.

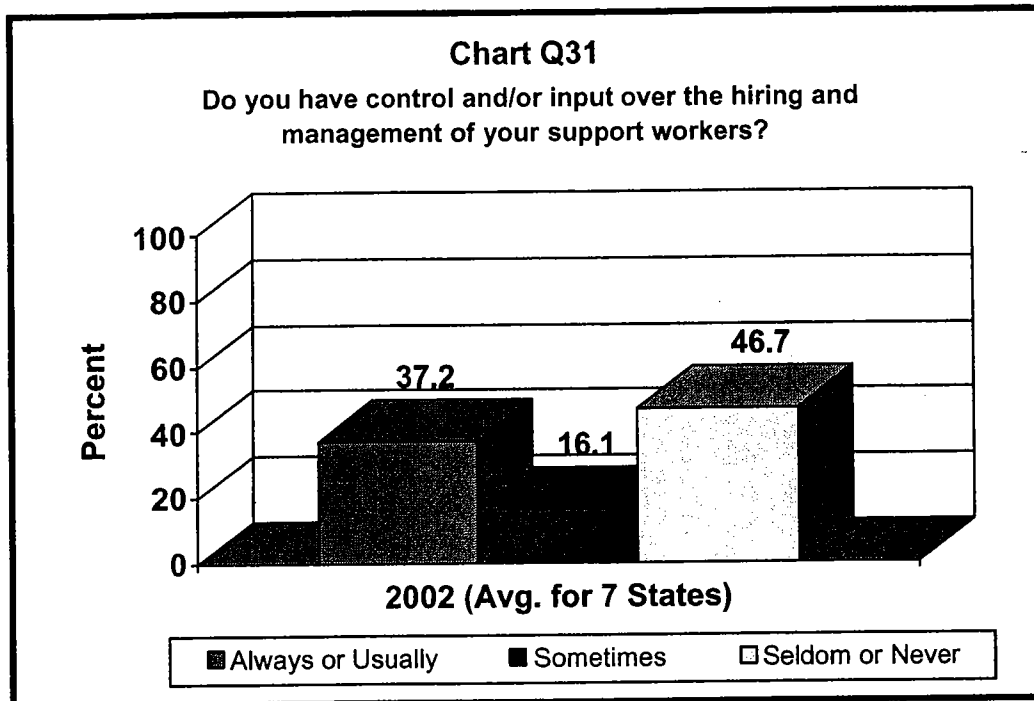


Table Q31
Do you have control and/or input over the hiring and management of your support workers?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓↓	26.8	16.7	56.5	239
CA-RCOC	↓↓↓	25.5	17.5	57.1	487
MA	↑	44.6	20.1	35.3	224
SC	↓	28.6	12.7	58.7	63
SD	↓↓↓	18.8	9.4	71.8	117
WA	↑↑↑	54.7	16.0	29.3	331
WY	↑↑↑	61.1	20.4	18.5	157
Total %		37.2	16.1	46.7	Total = 1611
State Average		37.2	16.1	46.7	Total = 1611

- ♦ While only 53% of respondents had at least some control over the hiring or management of their support workers, 83% wanted this type of control at least some of the time.

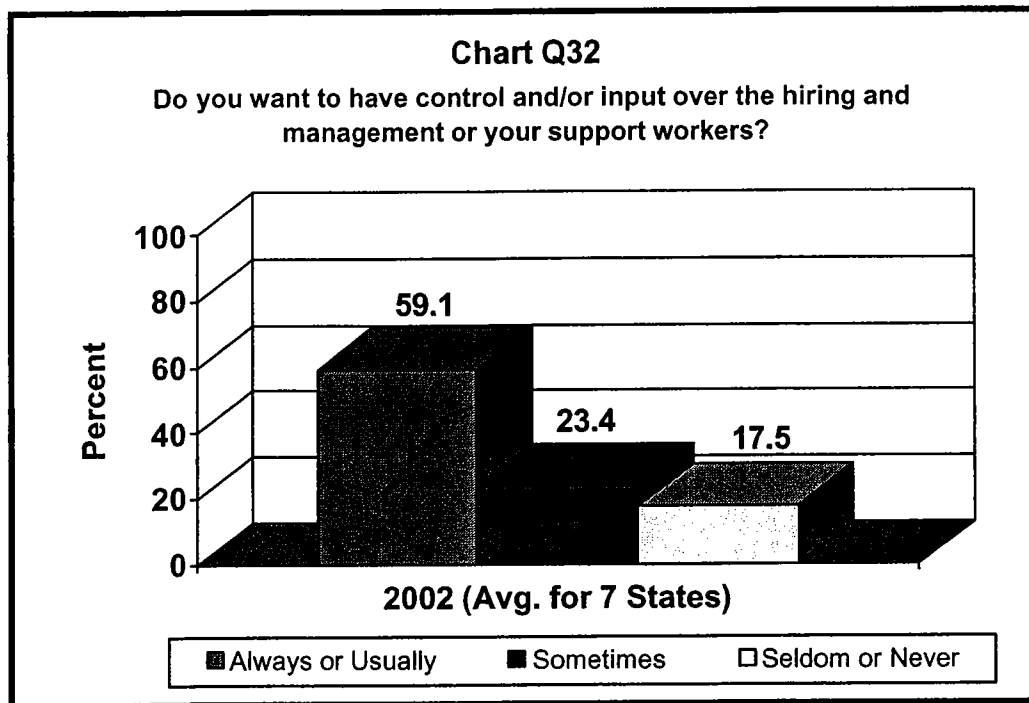


Table Q32

Do you want to have control and/or input over the hiring and management of your support workers?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		54.9	28.7	16.4	244
CA-RCOC		55.3	25.3	19.3	450
MA	↑	67.2	19.5	13.3	241
SC	↓	52.6	21.1	26.3	57
SD	↓↓	43.2	29.7	27.0	111
WA	↑	67.4	19.2	13.5	334
WY	↑↑	73.0	20.4	6.6	152
Total %		60.6	23.3	16.3	Total = 1,589
State Average		59.1	23.4	17.5	Total = 7

- ◆ Please note, due to Question 33's wording, "Don't Know" responses were interpreted to be similar in meaning and therefore included with the "Seldom or Never" responses. For this reason, states may notice higher responses in this category than in previous years.
- ◆ Only one-quarter (25%) of respondents knew how much money was spent by the MR/DD agency on behalf of their family member. Two-thirds (65%), however, had little or no idea.

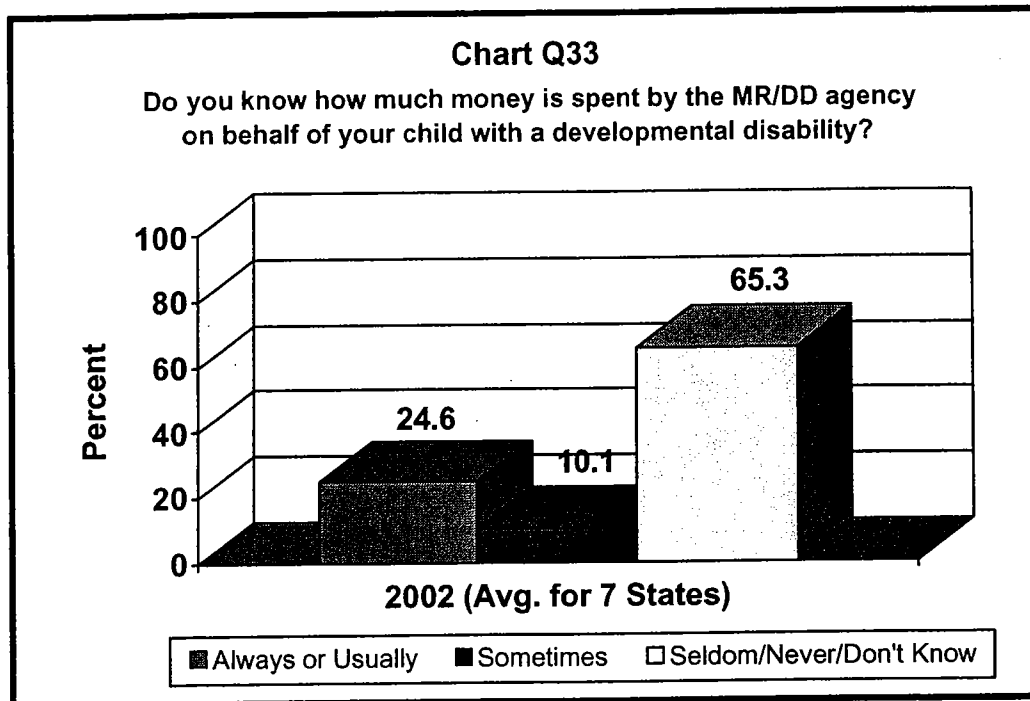


Table Q33

Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability?

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
AZ	↓↓↓	12.0	11.7	76.2	332
CA-RCOC	↓↓↓	14.5	6.6	78.9	800
MA	↑	29.6	9.1	61.3	328
SC	↓↓↓	14.3	2.0	83.7	98
SD		22.2	16.7	61.1	162
WA	↑	31.1	11.9	57.0	453
WY	↑↑↑	48.4	12.6	39.0	182
Total		22.6	9.7	67.7	Total = 2,455
State Average		24.6	10.1	65.3	Total = 7

- ♦ Overall, slightly more than half of the families surveyed (58%) had at least some decision-making authority over how the money available to their family member with disabilities by the MR/DD agency was spent. Forty-two percent, however, did not. Results varied considerably from state to state.

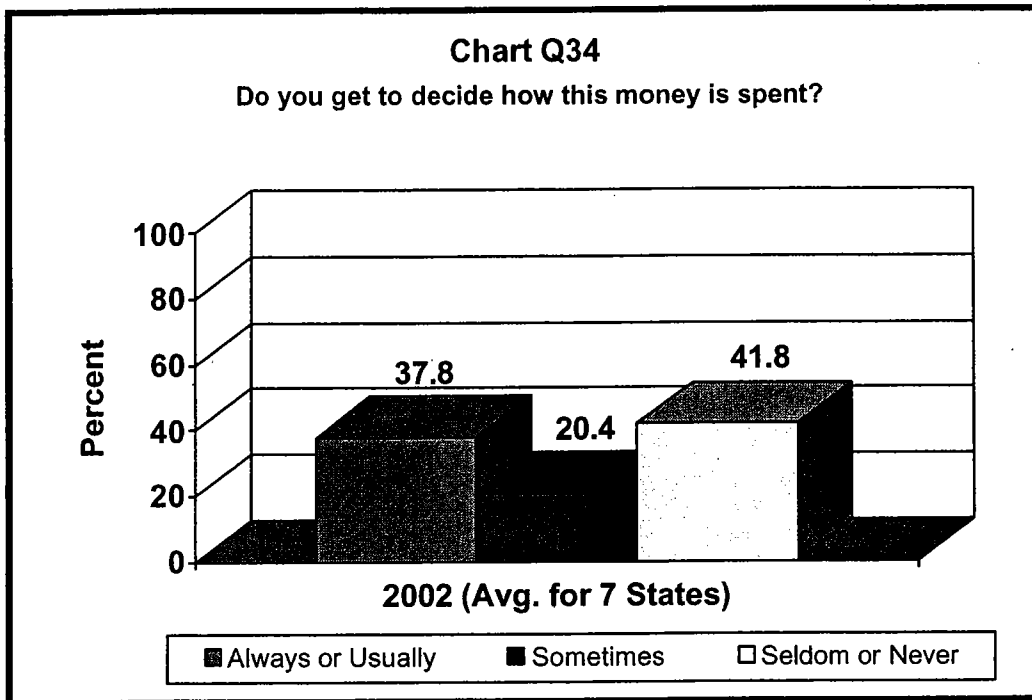


Table Q34
Do you get to decide how this money is spent?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓	7.6	12.8	79.6	211
CA-RCOC	↓↓	27.0	13.6	59.4	456
MA	↑↑	53.9	21.0	25.1	243
SC	↓↓	23.6	12.7	63.6	55
SD	↑↑	49.6	27.6	22.8	127
WA		39.4	31.0	29.6	358
WY	↑↑	63.3	24.1	12.7	158
Total %		36.5	20.6	42.9	Total = 1660
State Average		37.8	20.4	41.8	Total = 1660

Community Connections

- ♦ On average, one-quarter of respondents (26%) felt that planning or support staff were regularly available to help them use typical community supports (e.g., from a local health club, church or recreation activities) if desired. Another 29% said that staff were sometimes helpful, but 45% stated that planning and support staff were seldom or never helpful in connecting their family members to typical community supports or resources.

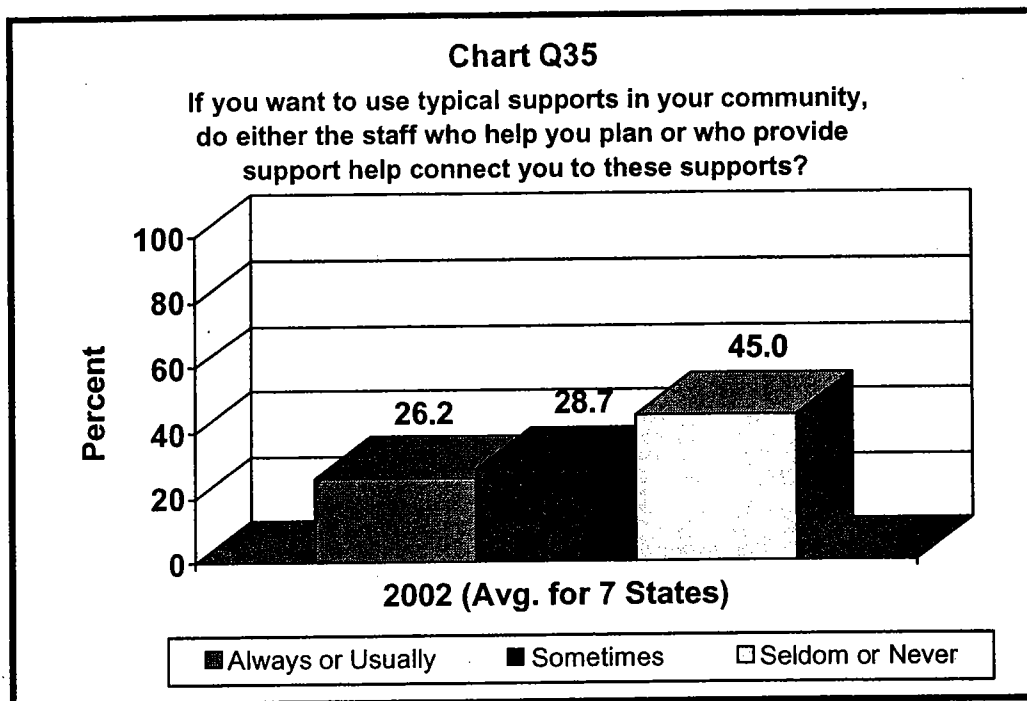


Table Q35

If you want to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help you plan or who provide support help connect you to these supports?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	26.4	26.9	46.8	216
CA-RCOC	26.6	27.3	46.1	534
MA ↓	21.0	24.7	54.3	243
SC ↑	34.5	22.4	43.1	58
SD	26.5	36.7	36.7	98
WA ↓	19.6	27.7	52.7	347
WY	29.0	35.5	35.5	138
Total %	26.2	28.7	45.0	Total = 1,336
State Average	26.2	28.7	45.0	Total = 1,336

- ♦ Overall, there was a split between respondents who indicated that staff helped them figure out how family, friends or neighbors could provide some of the families' needed supports (37% say yes, 39% say no, and the remaining 23% say it occasionally happens).

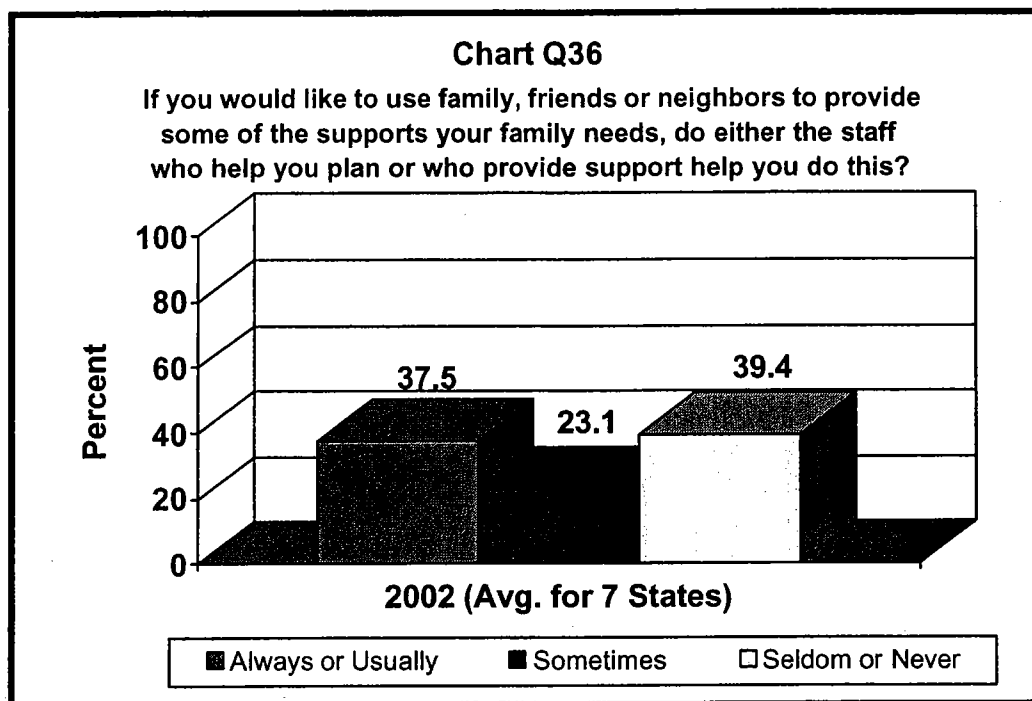


Table Q36

If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓	24.3	22.4	53.3	214
CA-RCOC	↓	32.1	24.6	43.4	505
MA	↓↓	27.4	22.6	50.0	230
SC	↑↑	53.0	18.2	28.8	66
SD	↑↑	52.2	24.8	23.0	113
WA	↓	32.5	27.1	40.4	354
WY		40.7	22.2	37.0	135
Total %		37.5	23.1	39.4	Total
State Average		37.5	23.1	39.4	Total

- ♦ Only 34% of families felt their family member always or usually had access to community activities. 26% stated their family member seldom or never had access to the community.

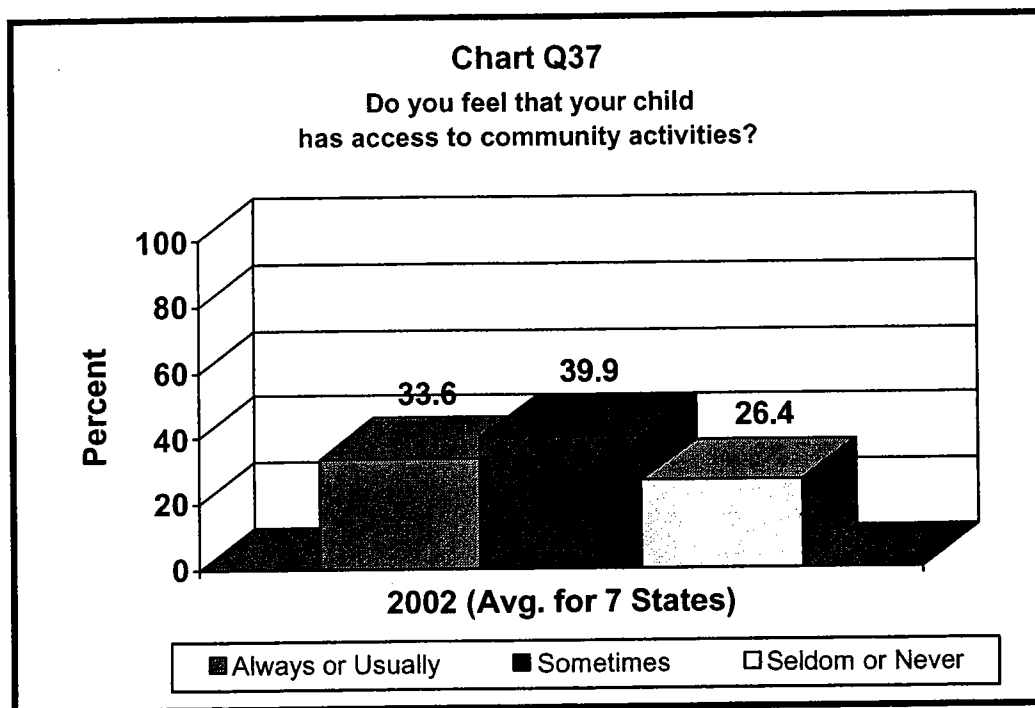


Table Q37
Do you feel that your child has access to community activities?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	40.6	37.1	22.4	286
CA-RCOC		30.7	38.2	31.0	670
MA	↓↓	21.6	43.5	34.9	347
SC	↑↑	47.7	29.5	22.7	88
SD		30.5	42.9	26.6	154
WA	↓	27.2	41.5	31.2	426
WY		37.1	46.6	16.3	178
Total %		31.4	40.3	28.3	Total = 2,121
State Average		33.6	39.9	26.4	Total = 2,121

- While 34% had regular access to community activities, only 20% of children regularly participated in them. Forty-one percent of respondents said that their child seldom or never participated in community activities or events ~ and these results were consistent across the states.

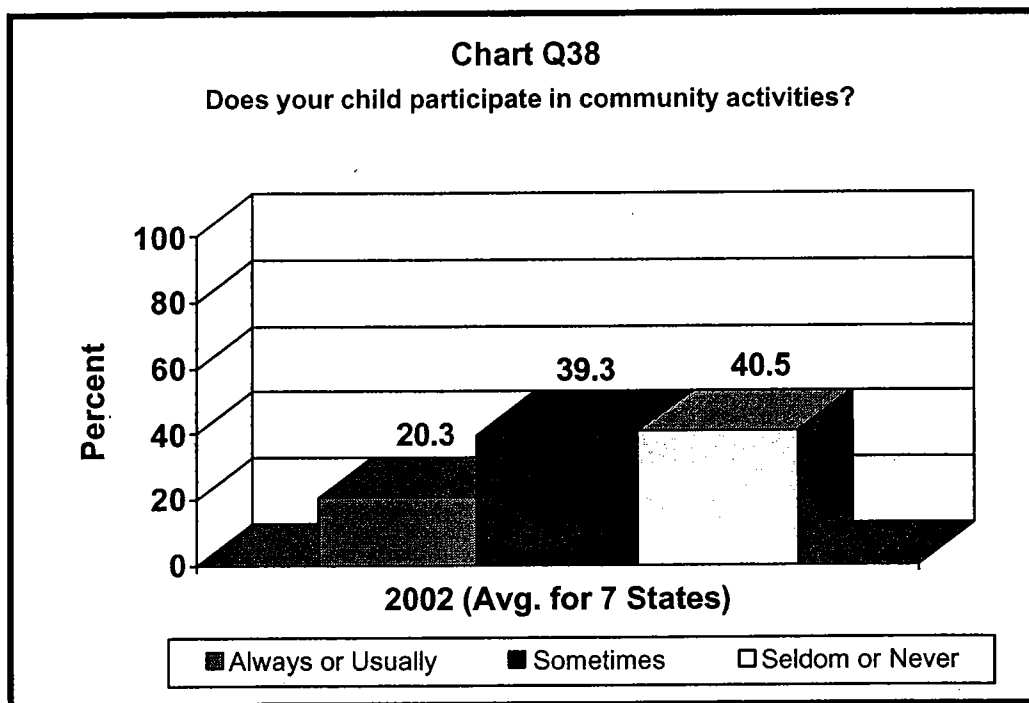


Table Q38
Does your child participate in community activities?

State	Always or Usually	Sometimes	Seldom or Never	n
AZ	23.7	35.2	41.1	304
CA-RCOC	19.2	37.7	43.1	677
MA	18.4	35.7	46.0	359
SC	23.9	34.1	42.0	88
SD	16.9	40.3	42.9	154
WA	16.8	41.8	41.4	435
WY	23.0	50.0	27.0	178
Total	19.5	38.9	41.6	Total = 2197
State Average	20.3	39.3	40.5	Total = 2197

- ♦ About half (52%) of respondents' children regularly spend time with children who do not have disabilities ~ which leaves the other half (48%) who only spend some or little time with children without disabilities.

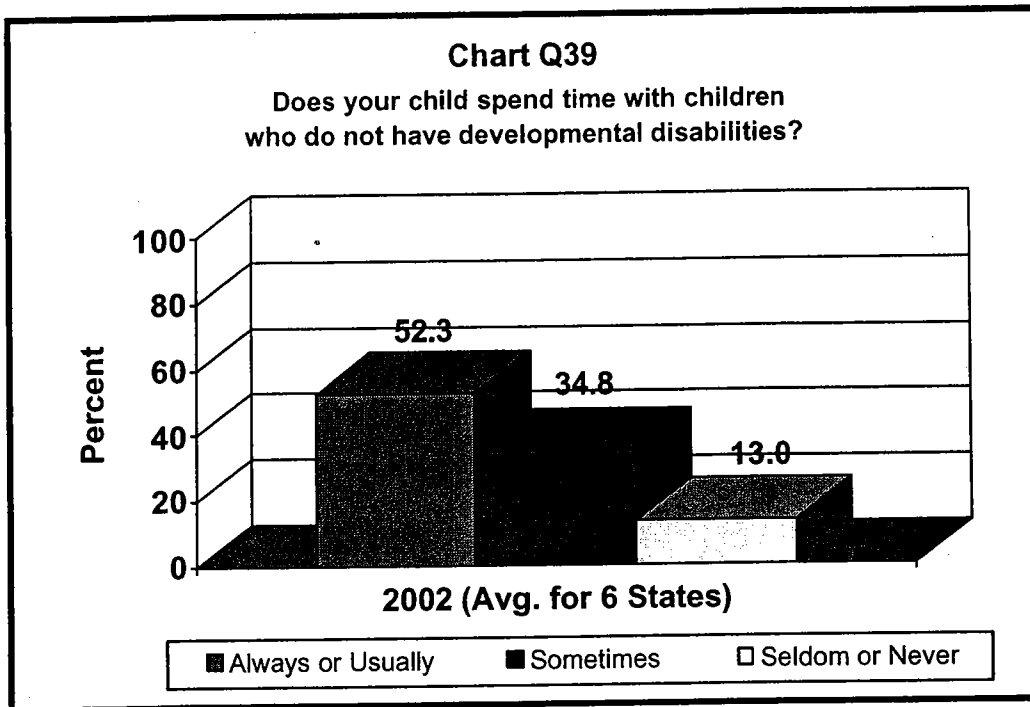


Table Q39
Does your child spend time with children who do not have developmental disabilities?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑↑	63.1	28.3	8.6	339
CA-RCOC		52.6	33.9	13.5	814
MA	↓↓	41.9	39.4	18.6	360
SC		* Question not asked			
SD		57.2	31.9	10.8	166
WA		47.6	37.5	14.9	464
WY		51.1	37.5	11.4	184
Total %		51.7	34.8	13.5	Total = 2,367
State Average		52.3	34.8	13.0	Total = 2,367

Outcomes and Satisfaction with Services and Supports

- Overall, 61% were always or usually satisfied with the services and supports they received. 32% were somewhat satisfied, and 7% were seldom or never satisfied.

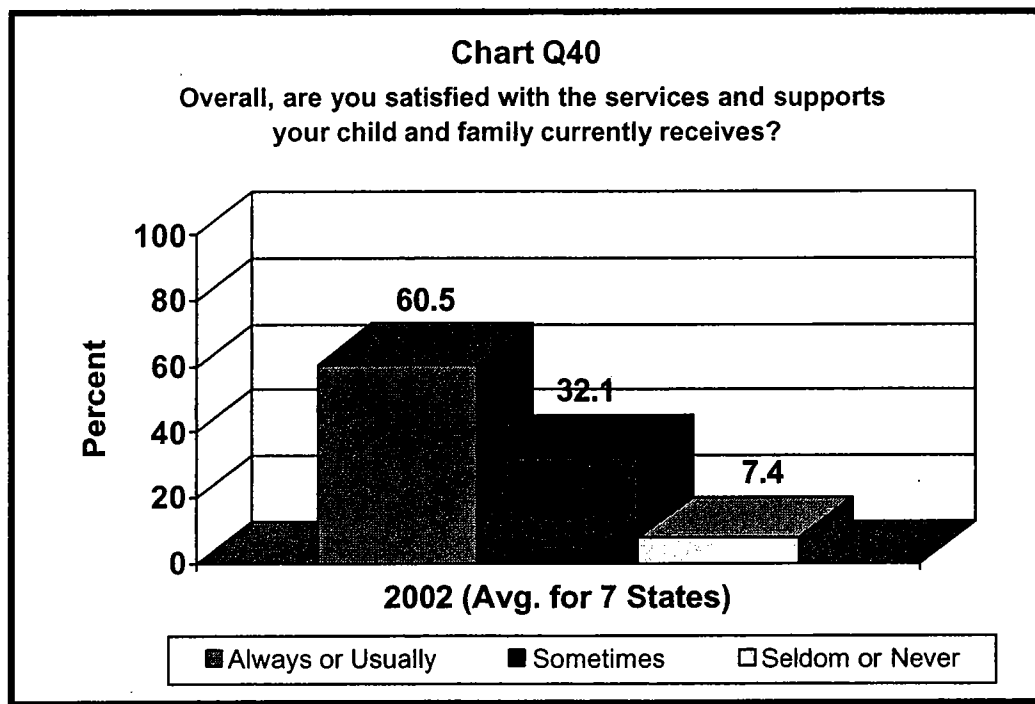


Table Q40
Overall, are you satisfied with the services and supports your child and family currently receives?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		62.2	33.6	4.2	336
CA-RCOC		56.5	33.5	10.0	811
MA	↓↓	41.4	40.8	17.8	331
SC	↑	65.9	27.5	6.6	91
SD	↑↑	82.6	16.2	1.2	167
WA	↓↓	47.6	43.4	9.0	456
WY	↑	67.2	29.5	3.3	183
Total		58.5	31.7	9.8	1,914
State Average		60.5	32.1	7.4	614

- ◆ Please note, due to Question 41's wording, "Don't Know" responses were interpreted to be similar in meaning and therefore included with the "Seldom or Never" responses. For this reason, states may notice higher responses in this category than in previous years.
- ◆ On average, only 37% of respondents knew about their agency's grievance process, while 51% had little or no familiarity with the process for lodging a complaint.

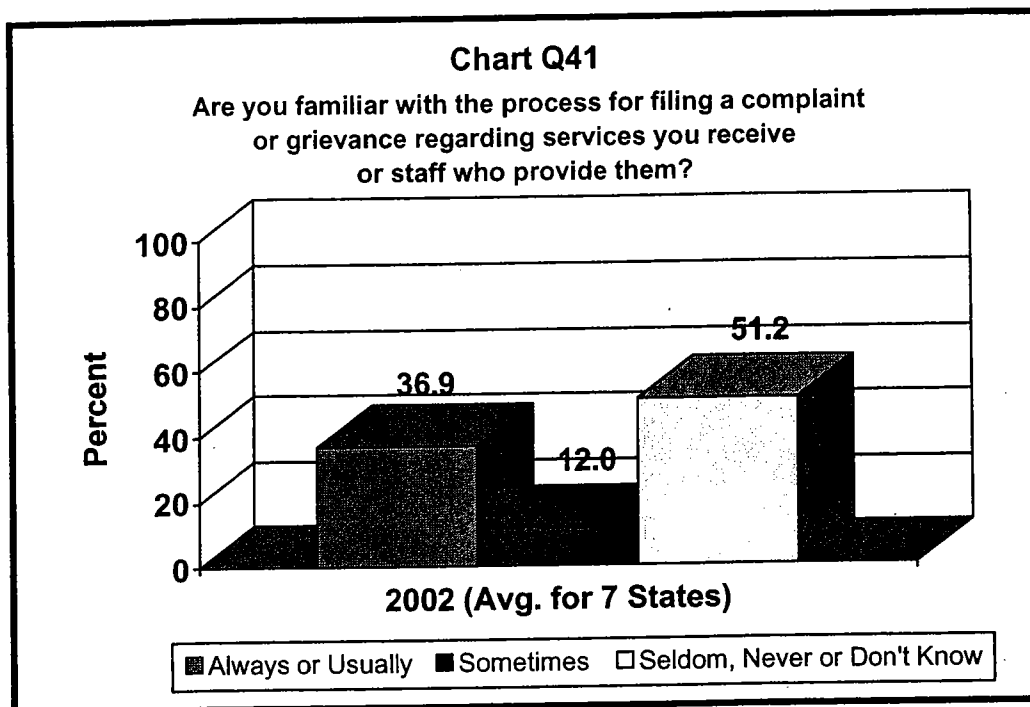


Table Q41

Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?

State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
AZ	↑	42.1	9.2	48.7	316
CA-RCOC		40.4	15.2	44.4	789
MA	↓	28.8	5.7	65.5	316
SC	↓	31.6	19.0	49.4	79
SD	↑	43.9	12.1	43.9	157
WA	↓↓	26.9	10.8	62.3	424
WY	↑	44.4	11.7	43.9	180
Total		36.9	12.0	51.2	2277
State Average		36.9	12.0	51.2	2277

- ♦ A slight majority of respondents (52%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 48%, however, were either not satisfied, or only sometimes satisfied with how these matters were resolved.

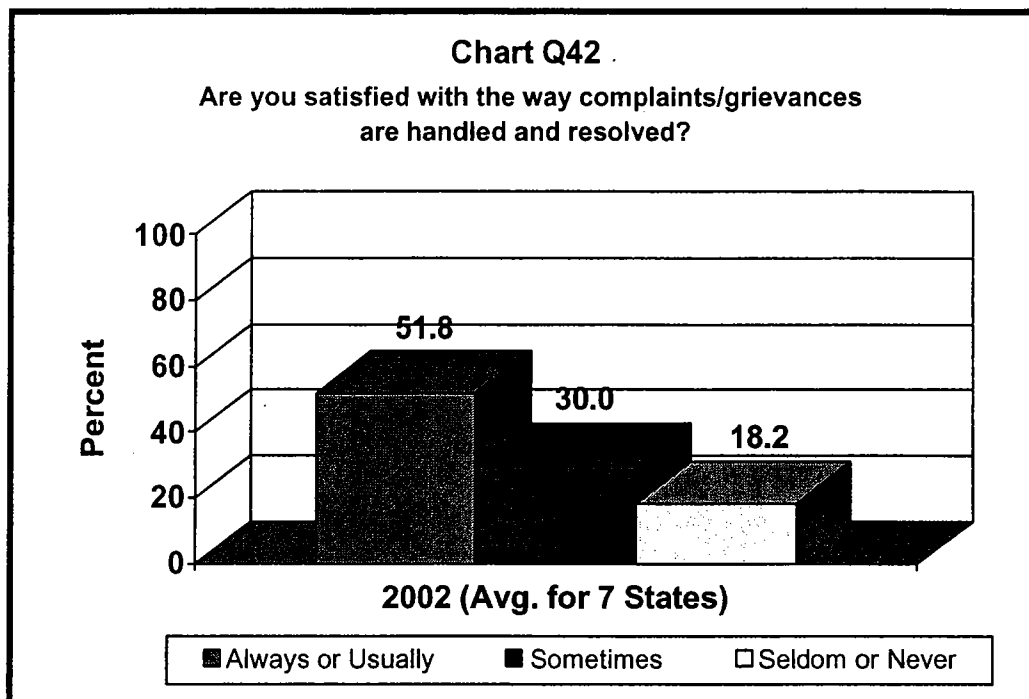


Table Q42

Are you satisfied with the way complaints/grievances are handled and resolved?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		50.4	29.4	20.2	119
CA-RCOC		49.4	33.2	17.4	328
MA		47.4	28.9	23.7	76
SC		54.3	26.1	19.6	46
SD	↑↑	65.4	25.0	9.6	52
WA	↓	44.7	32.7	22.7	150
WY		50.8	34.9	14.3	63
Total %		49.8	31.2	19.0	708
State Average		51.8	30.0	18.2	708

- ♦ Sixty-nine percent of families felt that services and supports have made a positive difference in their lives. Only 7% stated that they seldom felt this way.

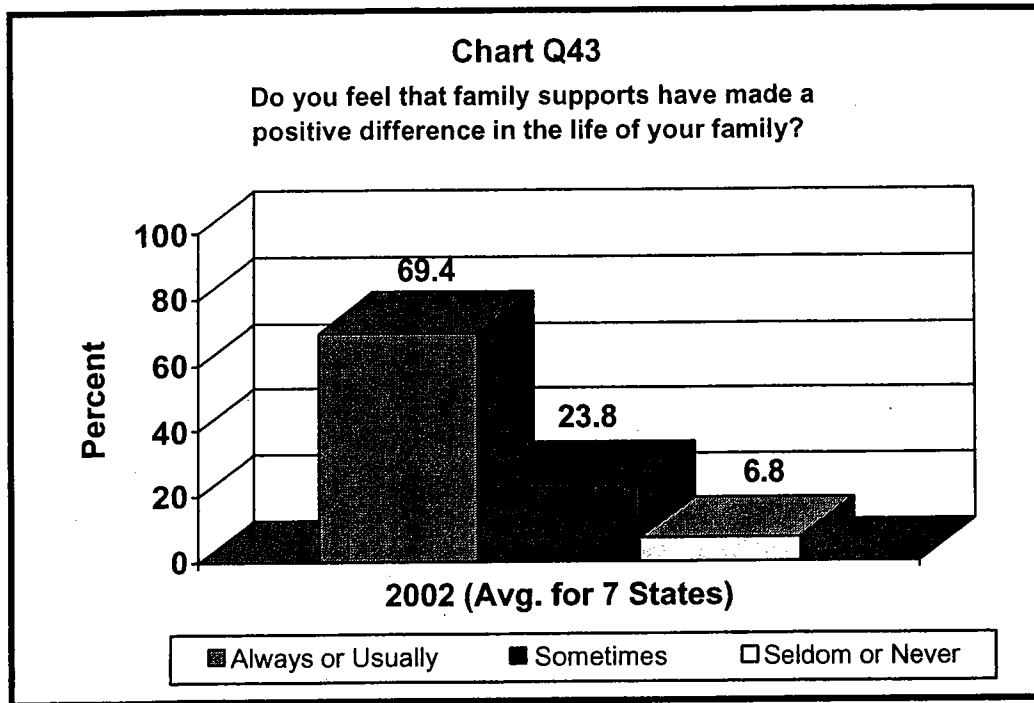


Table Q43
Do you feel that family supports have made a positive difference in the life of your family?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		67.0	27.8	5.2	306
CA-RCOC	↓	59.9	30.9	9.3	713
MA	↓↓	56.4	29.8	13.8	319
SC		71.4	20.9	7.7	91
SD	↑↑	92.2	7.2	0.6	167
WA		67.1	24.7	8.2	438
WY		71.8	25.4	2.8	177
Total %		65.7	26.4	7.9	Total = 2,211
State Average		69.4	23.8	6.8	Total = 2,211

- Nearly all families (91%) felt that family supports improved, to some extent, their ability to care for their child.

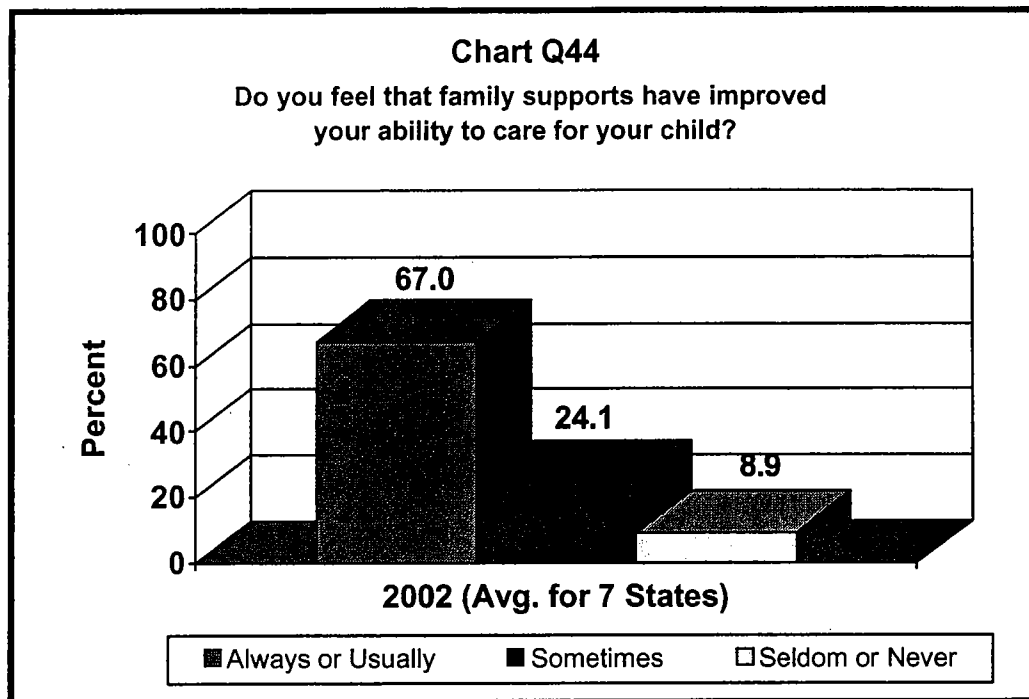


Table Q44
Do you feel that family supports have improved your ability to care for your child?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		67.9	23.9	8.2	305
CA-RCOC	↓	58.2	31.4	10.3	716
MA	↓↓	54.3	27.8	18.0	317
SC		64.8	26.1	9.1	88
SD	↑↑	89.2	7.8	3.0	166
WA		63.8	25.6	10.6	442
WY		70.6	26.0	3.4	177
Total %		63.7	26.3	10.0	1,811
State Average		67.0	24.1	8.9	1,811

- ♦ Three-fourths (73%) of respondents indicated that services have made a difference in helping them keep their child at home.

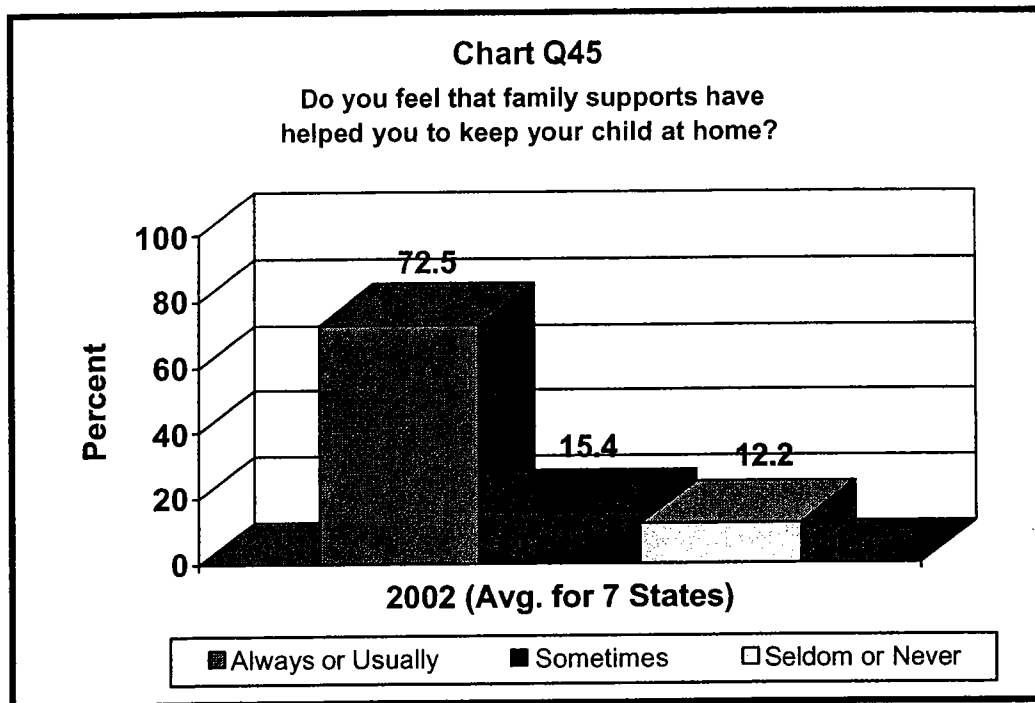


Table Q45
Do you feel that family supports have helped you to keep your child at home?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		73.1	15.8	11.1	253
CA-RCOC	↓	64.2	19.7	16.1	654
MA	↓↓	61.7	14.5	23.8	269
SC	↑	77.9	11.7	10.4	77
SD	↑↑	83.6	10.3	6.2	146
WA		69.1	15.1	15.8	392
WY	↑	77.8	20.4	1.9	162
Total		69.1	15.6	15.3	1,911
State Average		72.5	15.4	12.2	1,911

- ♦ Eighty-four percent of respondents felt that their family member was usually happy.

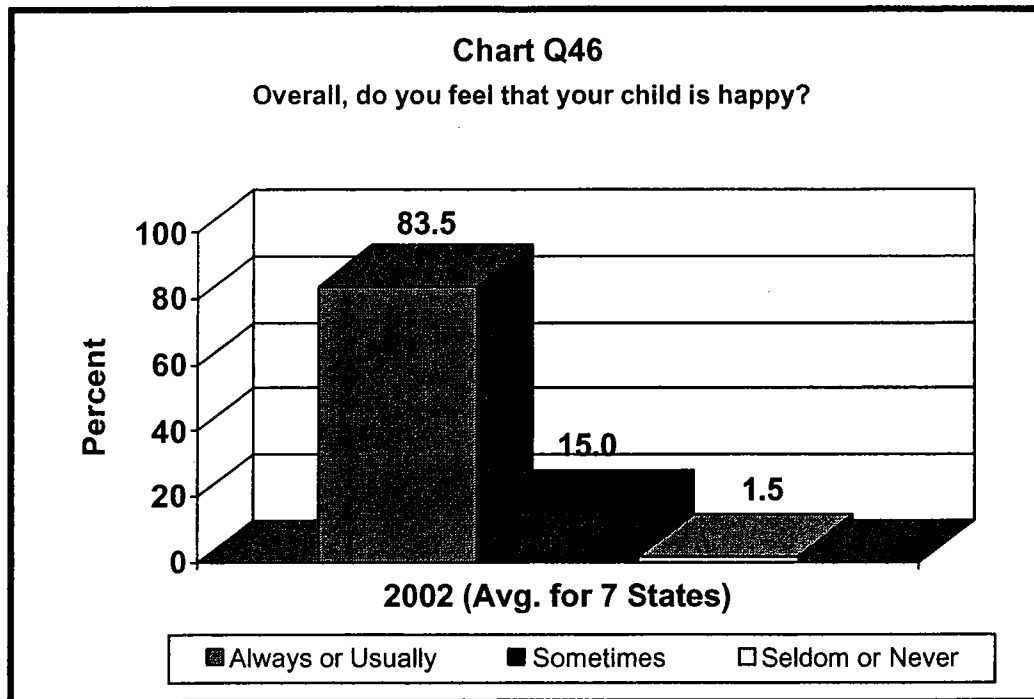


Table Q46
Overall, do you feel that your child is happy?

State		Always or Usually	Sometimes	Seldom or Never	n
AZ		86.4	12.7	0.9	338
CA-RCOC	↓	78.2	19.6	2.2	834
MA		78.7	18.0	3.4	256
SC		87.0	10.9	2.2	92
SD		88.2	11.8	0.0	170
WA		80.0	18.8	1.3	469
WY		86.3	13.1	0.5	183
Total %		81.4	16.9	1.5	Total n = 2,142
State Average		83.5	15.0	1.5	Total n = 2,142

Aggregate Results & State Trends

Above, the findings are displayed question by question. In this section, we look at survey findings by each categorical area of questioning (i.e., information and planning, access and delivery of services, choice and control, community connections, and overall satisfaction).

For each of these categories, there is a CHART that displays the State Average ~ indicating the average percentage, across states, of respondents who answered each question with an "always or usually" response. In nearly all cases, the higher this response, the more satisfied the respondents were with their supports.

For each category, there is also a TABLE that looks at the arrows (i.e., \uparrow and \downarrow) of the previous Tables, with single arrows representing state results $\pm 5\%$ from the state average, and double arrows ($\uparrow\uparrow$ and $\downarrow\downarrow$) representing $\pm 10\%$ from the state average.

This compilation of results (up arrows minus down arrows) provides a crude overview of trends, across states and within topic groupings (e.g., information and planning, choice and control), illustrating how states measured up, overall, against the state averages.

As a review, the first chart illustrates state averages, and the table that follows illustrates how states compared to these state averages.

Information and Planning

- ♦ In South Carolina, South Dakota and Wyoming, responses to information and planning questions were generally above the overall state average. In Massachusetts and Washington, results were generally below the state average.

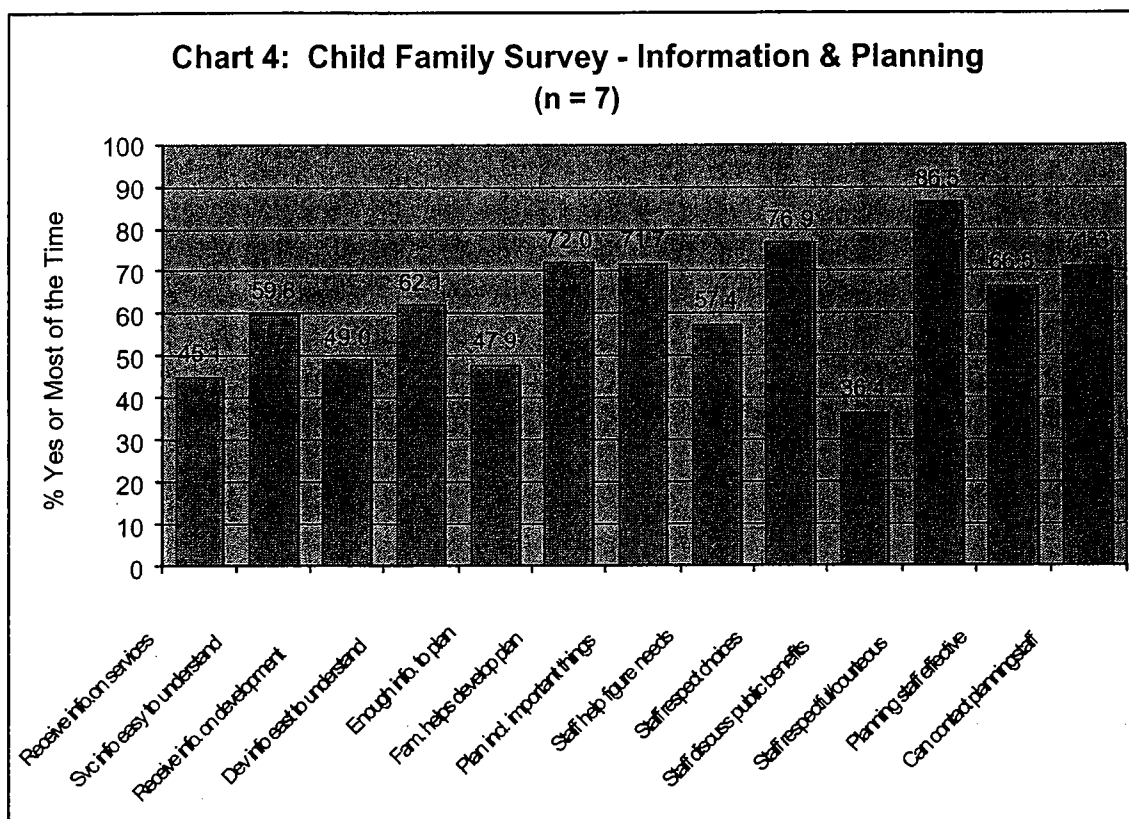


Table 17
Trends in Responses Above & Below State Average
Information & Planning

State	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Net Sum
AZ			↑↑	↑↑										4
CA-RCOC	↑↑	↑	↓			↓	↓↓	↓↓				↓		-4
MA	↓↓				↓↓	↓↓		↓↓	↓	↓↓		↓↓	↓	
SC			↑		↑↑			↑↑		↑↑		↑		
SD	↑↑	↑↑			↑↑	↑	↑↑	↑↑	↑	↑	↑	↑↑	↑↑	
WA	↓↓	↓↓	↓↓	↓↓	↓↓	↓	↓↓	↓↓	↓	↓		↓	↓↓	
WY		↓			↑	↑↑	↑↑	↑↑				↑	↑	

Access and Delivery of Services

- ♦ In South Carolina and South Dakota, responses to access and delivery of services questions were generally above the overall state average. In Massachusetts and Washington, results were generally below the state average. Note that Question 18 is considered a “neutral question”, and therefore, up and down arrows were not used in the calculation of state trends.

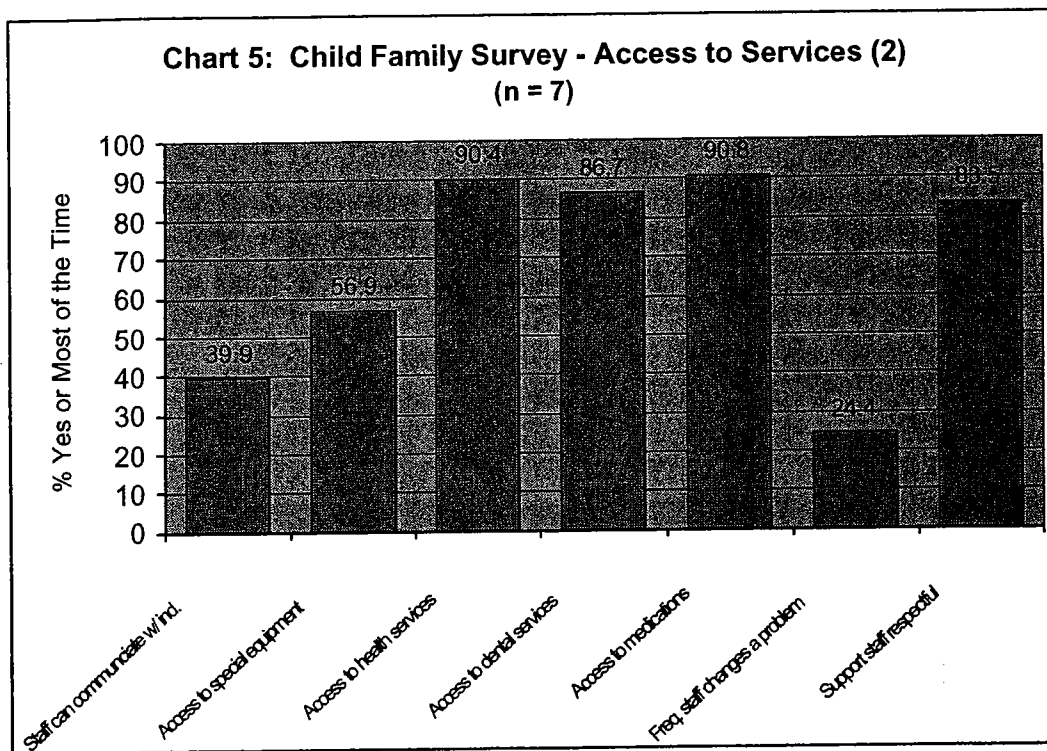
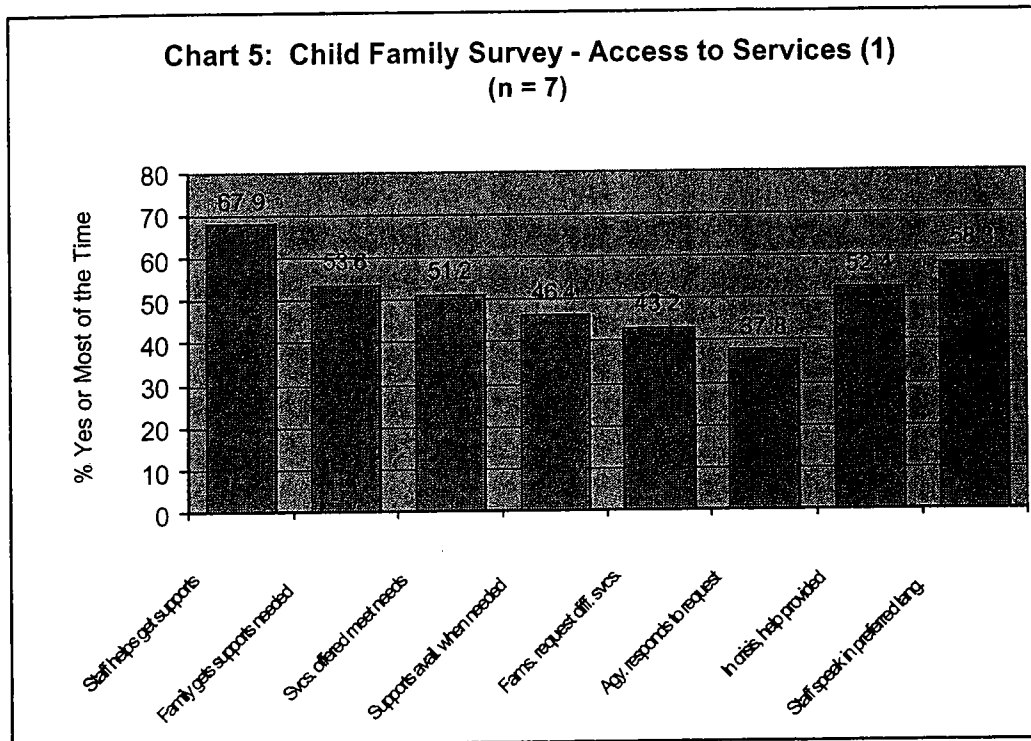


Table 18
Trends in Responses Above & Below State Average
Access to Services & Supports

State	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Q27	Q28	Net Sum
AZ							↓↓									-2
CA-RCOC	↓↓		↓			↓			↑↑		↓		↓	↓↓	↓↓	-8
MA	↓↓	↓↓	↓↓	↓↓					↓	↓						
SC		↑	↑	↑		↑	↑	↑↑	↑↑					↑		
SD	↑↑	↑↑	↑↑	↑↑		↑↑	↑↑	↓	↓↓	↑↑	↑		↑	↑↑	↑↑	
WA		↓↓	↓↓	↓↓		↓↓	↓↓		↓↓	↓↓						
WY	↑↑		↑			↓		↓	↓	↑						1

Choice and Control

- ♦ In this category, every state scored either considerably above or below the state average, indicating that there was very little middle ground when it came to choice and control. In Massachusetts, Washington and Wyoming, responses to choice and control questions were generally above the overall state average. In Arizona, Orange County, California, South Carolina and South Dakota, results were generally below the state average.

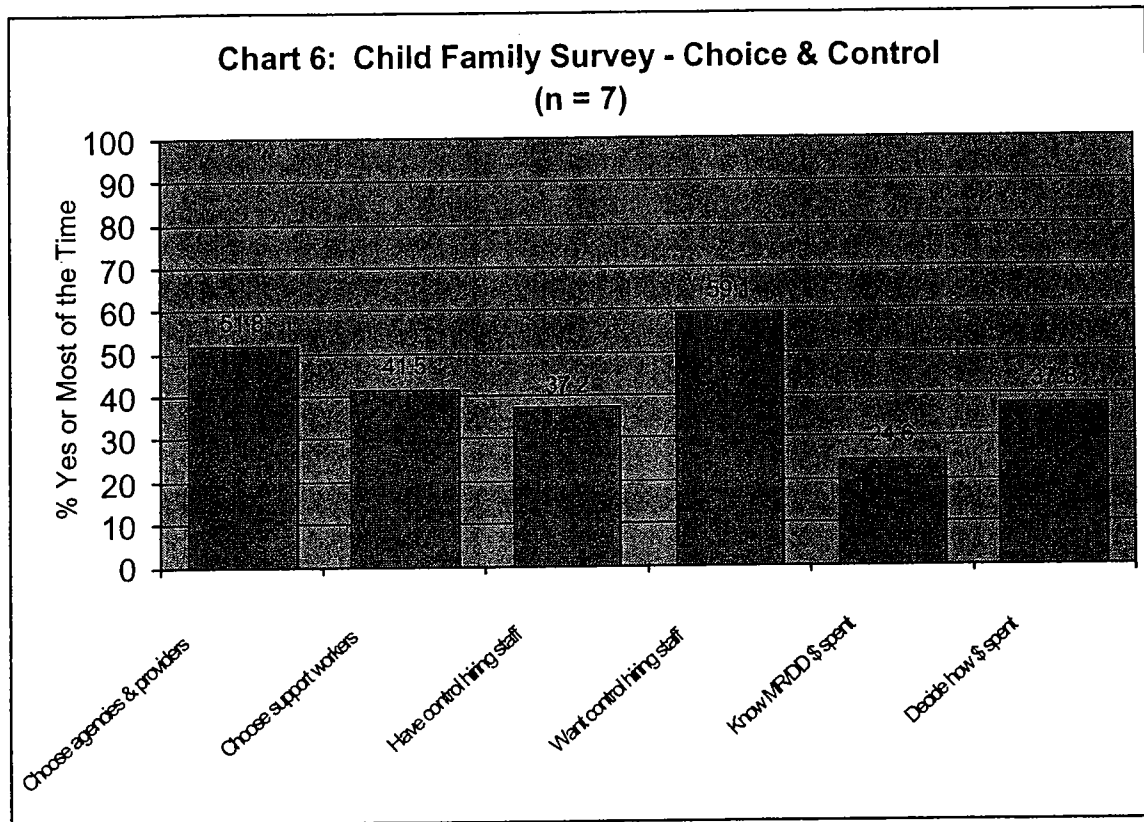


Table 19
Trends in Responses
Above & Below State Average
Choice & Control

State	Q29	Q30	Q31	Q32	Q33	Q34	Net Sum
AZ	↓↓	↓	↓↓		↓↓	↓↓	
CA-RCOC	↓↓	↓↓	↓↓		↓↓	↓↓	
MA			↑	↑	↑	↑↑	
SC		↑	↓	↓	↓↓	↓↓	
SD	↓↓	↓↓	↓↓	↓↓		↑↑	
WA	↑		↑↑	↑	↑		
WY	↑↑	↑↑	↑↑	↑↑	↑↑	↑↑	

Community Connections

- ♦ In South Carolina, responses to community connections questions were generally above the overall state average. In Massachusetts and Washington, results were generally below the state average.

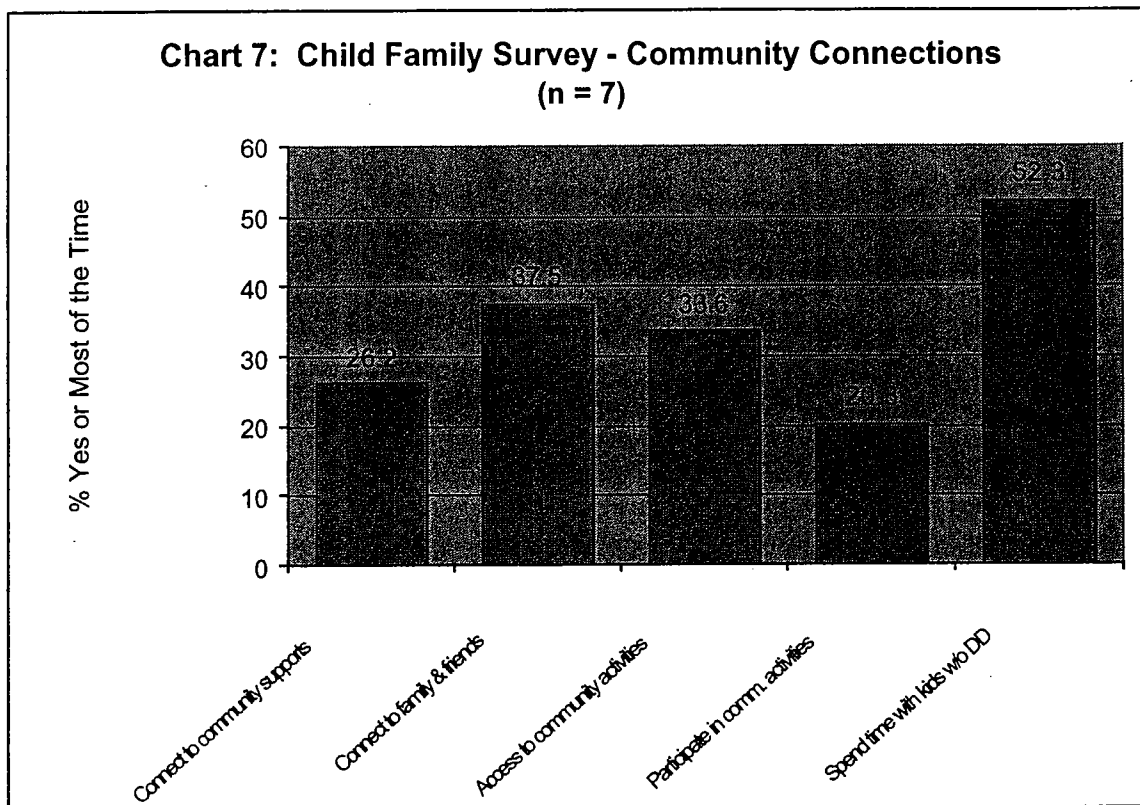


Table 20
Trends in Responses
Above & Below State Average
Community Connections

State	Q35	Q36	Q37	Q38	Q39	Net Sum
AZ		↓↓	↑		↑↑	1
CA-RCOC		↓				-1
MA	↓	↓↓	↓↓		↓↓	
SC	↑	↑↑	↑↑			
SD		↑↑				2
WA	↓	↓	↓			
WY						0

Satisfactions with Services and Supports & Outcomes for Families

- ♦ In South Dakota, responses to satisfaction with services and outcomes for families questions were generally above the overall state average. In Orange County, California, Massachusetts and Washington, results were generally below the state average.

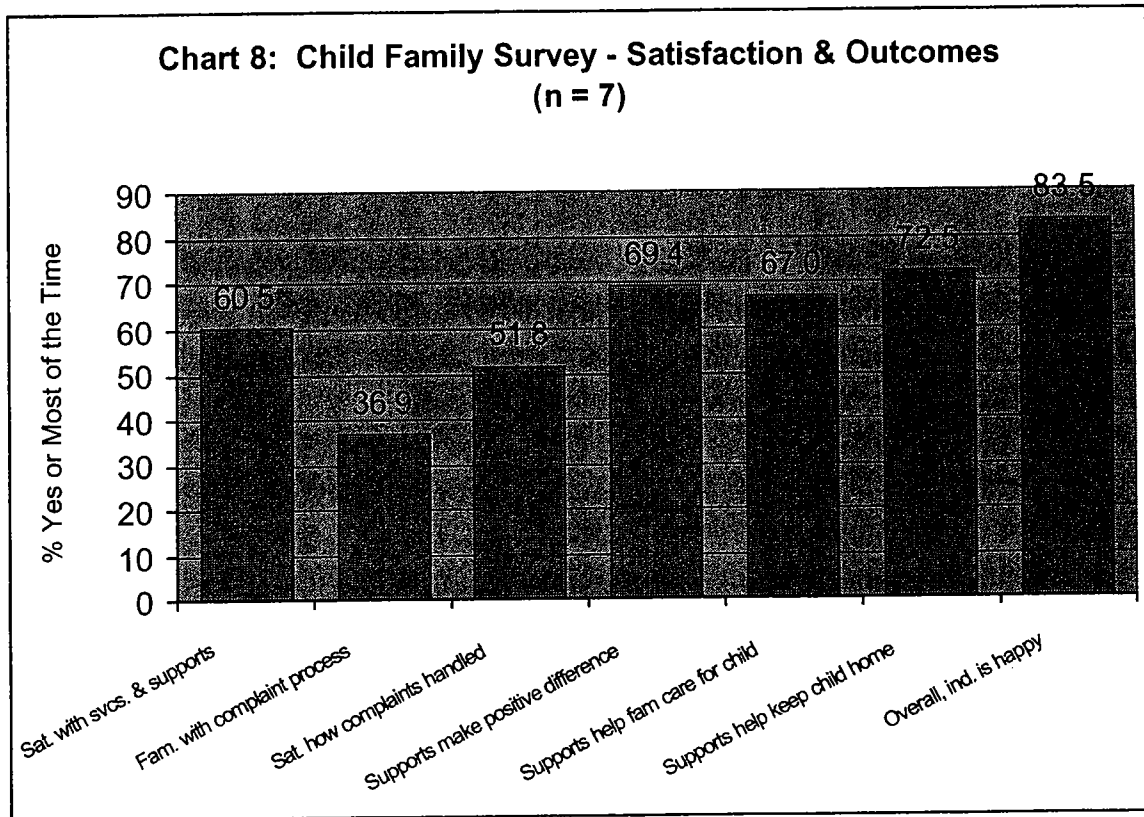


Table 21
Trends in Responses
Above & Below State Average
Satisfaction & Outcomes

State	Q40	Q41	Q42	Q43	Q44	Q45	Q46	Net Sum
AZ		↑						1
CA-RCOC				↓	↓	↓	↓	
MA	↓↓	↓		↓↓	↓↓	↓↓		
SC	↑	↓				↑		1
SD	↑↑	↑	↑↑	↑↑	↑↑	↑↑		
WA	↓↓	↓↓	↓					
WY	↑	↑				↑		3

Overall State Trends

- ♦ Looking at results across all categories, South Dakota and Wyoming had results that were generally above the overall state average. In Orange County, California, Massachusetts and Washington, results were generally below the overall state average.

Table 22 Overall Trends in Responses Above & Below State Average	
State	Total Sum
AZ	-6
CA-RCOC	
MA	
SC	18
SD	
WA	
WY	